

Participatory research with adults with Asperger's syndrome: using spatial analysis  
to explore how they make sense of their experience

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## **Abstract**

This thesis explores participatory research involving the author and a small group of adults with Asperger's syndrome, as co-researchers. The research was based on the assumption that people with Asperger's syndrome think differently from neuro-typical people (people who do not have Asperger's syndrome or autism). It is not denied that people with Asperger's syndrome have difficulties, but the thesis argues that these are caused by living in a world which is dominated by neuro-typical people who do not understand or allow for the differences that people with Asperger's syndrome have. The research is based on the assumption that adults with Asperger's syndrome are able to be co-researchers and that part of the task of the researcher and the co-researchers was to find a way of working together that was enabling to all involved in the research.

The original aim of the research was to ascertain what kind of service provision adults with Asperger's syndrome wanted and this formed the research question: 'What support do adults with Asperger's syndrome want?' The findings of the research challenge traditional notions of support as the emphasis is taken away from support to consider forms of understanding. It has resulted in the proposal of a new way of understanding Asperger's syndrome. It proposes models for understanding how people with Asperger's syndrome and neuro-typical people relate to each other. These models challenge a currently prevailing deficit-based understanding of Asperger's syndrome.

The author and the co-researchers worked collaboratively to design research tools, collect and analyse data and disseminate findings. The data was collected from other adults with Asperger's syndrome who took part in questionnaires and then different adults with Asperger's syndrome who took part in a focus group and individual interviews.

The work was informed by the literature on spatial understandings of how society is ordered. The thesis uses this spatial understanding as a way of analysing how people with Asperger's syndrome are regarded in a society which is dominated by people who are neuro-typical. Insights from a spatial understanding are also used to consider the process of the research, including an application of the social model of disability to participatory research involving adults with Asperger's syndrome. My original contribution to knowledge is that I have demonstrated that people with Asperger's syndrome have the potential to work in group situations on a complex piece of research. I have shown that people with Asperger's syndrome are able to make a significant contribution to the understanding of how people with Asperger's syndrome and neuro-typical people relate to each other.

I have also demonstrated how a non-disabled researcher and co-researchers with Asperger's syndrome can work together and devise working methods which are enabling. In the words of the thesis, I have demonstrated how an 'autistic research space' can be created. This thesis discusses the role of the neuro-typical researcher in the creation of this research space. The research is regarded as having been co-produced and the meaning of this is explored.

The thesis discusses the nature of participatory research using a spatial understanding. Emancipatory research is said to be based on the social model of disability, where non-disabled researchers are not involved. I have shown that participatory research can also be based on the insights from the social model of disability and achieve the outcomes required for emancipatory research. I have proposed a framework for planning and analysing participatory research.

Perhaps the most significant contribution to knowledge is the new way of understanding Asperger's syndrome proposed by the research which challenges the more traditionally accepted deficit based model.

## Introduction

The impetus for this PhD thesis came from my interest in and experience of supporting people with Asperger's syndrome. Before commencing my post at De Montfort University as a lecturer in social work 2005, I worked in a number of different teams where part of my role as a social worker and then team manager was working with adults and children with Asperger's syndrome and their families and carers. I also had personal experience of Asperger's syndrome as a number of close family members had received that diagnosis. In addition I had attended a year long training course at a special school for pupils with autism about autism and Asperger's syndrome while I was a social work practitioner. From these experiences I had formed the opinion that adults with Asperger's syndrome did not always find it easy to gain support, especially as many services argued that anyone with Asperger's syndrome does not 'fit' their criteria. Whilst I was a practitioner, there was much debate about whether people with Asperger's syndrome should be provided with services under the auspices of mental health services or learning disability services. Neither of these seemed satisfactory as Aspergers's syndrome should not properly come under the remit of either of these services. Some local authorities have made the decision to provide a specialist social work team for adults with Asperger's syndrome, whilst many have not done this. As well as the question of who should provide support, I also had long pondered the more important question of **how** adults with Asperger's syndrome should best be supported. When I came to work at De Montfort University, part of my role as programme leader on a post qualifying social work programme involved working with service users. They became an integral part of the programme which I managed. I had not had the opportunity of working with service users in a strategic way as a practitioner, although making service users the centre of all decisions about them had always been my aim. I wanted to use my new experience of working with service users in a more strategic way in order to attempt to answer my questions about how people with Aspergers's syndrome should best be supported. I decided that I would like to embark on a piece of research to try and answer my questions.

As a student social worker and then as a social work practitioner I had been very influenced by the social model of disability and particularly by the writings of Michael Oliver. However, I had always thought that the social model of disability was easier to apply to people with a physical impairment. I wanted to explore how I could utilise this model in working with adults with Asperger's syndrome in research. I was not aware of any examples of this and I was keen to explore whether the social model could be used as a basis for working with a group of adults with Asperger's syndrome. I thought that there would be challenges in relation to working in a group situation as the literature and my own experience of supporting people with Asperger's syndrome indicated that typically those with Asperger's syndrome have difficulties in communication and coping with social situations. I had not come across any literature which discussed how people with Aspergers's syndrome relate to each other, just how they might relate to neuro-typical people (people who do not have autism or Asperger's syndrome). I wanted to work in a participatory way with people with Asperger's syndrome. I really did not know how this would work or even if I had the skills to make it work, but I was keen to try and put my principles of working in a participatory way to the test. I was also keen to explore whether the social model of disability is relevant to groups of people other than physically disabled people.

From my experience and knowledge of working with children and adults with Asperger's syndrome, I knew that they perceive the world in a different way to neuro-typical people. I wanted to be involved in forming a group of adults with Asperger's syndrome where group processes were conducted in such a way that was supportive of their cognitive differences. I had some ideas drawn from my experience about how this might work, but I also knew that each person with Asperger's syndrome is unique and I did not want to make assumptions. I considered that participatory research where all members of a group would be involved in every stage of the research was the most appropriate way to find out the views of service users. I was very aware that I do not have Asperger's syndrome and did not want to interpret what people with

Asperger's said in a neuro-typical way. Although I have some appreciation of what it is like to be a person with Asperger's syndrome through talking to people, reading, observations and family experience, I cannot think like one and would not presume to have insights which I believe only people with Asperger's syndrome could have. I set myself three main objectives for this piece of research at its commencement, although the actual formation of them in their current form was at a later date:

1. Use a participatory approach to explore how adults with Asperger's syndrome make sense of their experience of living in a neuro-typical world of living in a neuro-typical world.
2. Reflect on the use of the participatory research approach with adults with Asperger's syndrome.
3. Reflect on how the principles of participation can be most usefully applied in other contexts so that adults with Asperger's syndrome are able to reflect on their experiences and express what they need from services.

These all relate to my research question: 'What support do adults with Asperger's syndrome want?' The first aim addresses the perspective of adults with Asperger's syndrome, which is needed to understand how they view their need for support. The second aim is to reflect on the approach taken to conduct the research and the third aim is to examine how our findings can be applied. These objectives have not moved away from the original research question, but have broadened it to include a consideration of methodology and application of the research. From the findings of the research a set of issues emerged that actually challenge conventional views of support. Although it might seem contradictory that a thesis designed to explore the needs of adults with Asperger's syndrome for support actually resulted in a challenge to traditional ideas of support, this is a result of the methodology. The research was conducted in an open and participatory way and this allowed for new concerns to emerge during the research process. This in no way devalues the findings. They are still

directly relevant to the question of support as one of the key findings has been to reframe how support is understood.

After discussing my ideas with my supervisory team and gaining ethical approval, I formed a group with three adults with Asperger's syndrome. The contacts were gained through attending a support group for people with Asperger's syndrome and their carers and through recommendations of social workers. The group decided to call itself 'The Aspergers Consultation Group' (ACG). We agreed how we were going to work together and discussed the issue of support that I had wanted to explore. The group divided the topic of 'support' into different areas that they thought were important and these formed the basis of the sections of our questionnaire. A key discussion at the beginning of working together was the social model of disability and my contention that they were the experts as they are adults with Asperger's syndrome. This was important as subsequent discussions with the group evidenced how this set the tone and was crucial to their contributions. As a group we designed questionnaires which were sent to other adults with Asperger's syndrome who lived in the county where the research was to take place. We received 20 responses (10%). The group analysed the data together and designed questions for focus groups/individual interviews based on the responses to the questionnaires. Group members took part in the focus groups and individual interviews. One member of the group transcribed the data and the group as a whole worked on analysing the new data. The group and I held a conference in July 2012 to disseminate the results of the research to an audience of ninety three people which included adults with Asperger's syndrome, carers, parents and professionals and from senior management, the Director of Adult Social Services for the local authority involved.

### **Theoretical perspectives-the concept of space**

Early on, I identified the concept of space as being one which would be useful to analyse how adults with Asperger's syndrome chose to have a say in the services they received. Foucault's work has particular resonance as he used historical examples to

show how people can be categorised and how thinking about them changed. He wrote about how knowledge and power are linked as knowledge is produced to reinforce current thinking about groups of people e.g. in asylums and prisons (Foucault 1988 and Foucault 1989b). This is relevant to my study as there is a huge body of literature about Asperger's syndrome which has placed people with Asperger's syndrome as being outside of society by virtue of their impairments in communication and social understanding. This 'othering' has influenced how people with Asperger's syndrome are viewed and also how they view themselves, as I will show in Chapter One.

The concept of space is useful as it is a way of thinking about how groups of people can be put in 'spaces' which are not thought of as part of society. For Foucault, this was the asylum or the prison where dominant knowledge was reinforced through practice. For disabled people, this was in asylums (this will be explored in Chapter Three). For people with Asperger's syndrome, their 'space' is apart from people who are neuro-typical but not necessarily physically apart. They are 'othered' and forms of intervention are concerned with supporting them to 'pretend to be normal', to cite a book title on Asperger's syndrome (Willey, 1999). Although they are in a space through diagnosis that demonstrates them to be 'deficient', they are expected to learn to conform and inhabit the space of people who are neuro-typical. The findings of this research challenge this and although the adults with Asperger's syndrome who took part agreed that they are different from people who are neuro-typical, they saw the need for support to be about mutual understanding. Rather than a deficit model, it is often the lack of understanding on the part of people with Asperger's syndrome **and** people who are neuro-typical that causes difficulties and this leads to an inability to function well or even to cope. It is through **mutual** understanding that people with Asperger's syndrome will be able to function well and feel comfortable in society. People with Asperger's syndrome do not want to deny that they inhabit another 'space' but it is possible to have the two spaces overlapping so that mutual understanding and inclusion can take place. These concepts will be explored in more detail in the chapters that constitute the Literature Review.

## Policy context

Since commencing my research there have been significant policy developments in relation to autism. The *Autism Act 2009* sets out the duty of the Secretary of State to write and publish an autism strategy which indicates how services should be improved for adults with autism (*Autism Act, 1 (1)*). Three of the areas that Guidance issued under the Act covers are the need for:

- planning in relation to the provision of relevant services to persons with autistic spectrum conditions as they move from being children to adults (s. C);
- other planning in relation to the provision of relevant services to adults with autistic spectrum conditions (s. D);
- the training of staff who provide relevant services to adults with such conditions. (*Autism Act, s. A*).

To comply with this legislation, *Fulfilling and Rewarding Lives: the Strategy for Adults with Autism in England* was published (Great Britain. Department of Health (2010)) .

Three of the areas that this addressed are also relevant to this research:

- improved training of frontline professionals in autism
- actions for better planning and commissioning of services, including involving people with autism and their parents/carers
- actions for improving access to diagnosis and post-diagnostic support

This research has relevance for all three of these areas. Firstly, it offers a new framework for thinking about supporting people with Asperger's syndrome and so has implications for the training of staff. Secondly, it demonstrates ways of working with adults with Asperger's syndrome. Thirdly, it has relevance for post-diagnostic support as it proposes a model on which to base this, based on understanding. The strategy was reviewed with the *Think Autism Strategy 2014*. This has three new proposals, one of which is to create 'Autism Aware Communities'—these are described as 'Think Autism community awareness projects' and will 'be established in local communities'. The theory developed as part of this research has a direct bearing on this as it suggests



that mutual awareness and understanding is needed, not simply an awareness of autism. The strategy does suggest the desirability of communities where neuro-typical people are aware of the needs of people with autism. However, the proposal is that projects are established in communities which promote an awareness of autism. This is not necessarily the same as having communities where people with autism are understood. 'Awareness' is not synonymous with 'understanding', it implies a more superficial view as awareness is possible without understanding. This thesis will demonstrate the need to understand the individual and the individual experience of being a person with Asperger's syndrome. This is more important than any technical understanding of the condition itself.

## **Terminology**

Throughout this thesis, I will refer to myself as a 'researcher' and the adults with Asperger's syndrome who formed the group I worked with as 'co-researchers'. I was initially unsure about the term 'co-researcher' as I thought it might suggest an inferior position in the research to my own. Some literature refers to 'user-led' research but this did not seem an appropriate term as it is used to refer to service users who have come together to share experiences and have campaigned for changes (Barnes and Cotterell, 2012, p. 145). This did not fit with my methodology which involved myself as a non-disabled researcher working together with the co-researchers. Another choice would have been to refer to the co-researchers as 'members of the Asperger's Consultation Group' or 'adults with Asperger's syndrome'. Some writers refer to people who were included in research in this way, for example, referring to 'young mothers' (Brady, Brown and Wilson, 2012). I did not want to do this as I wanted to use a term which identified them more closely with the research process. Other writers refer to 'lay researchers'. Nind explains the rationale for this choice as being: '...it offers a distinction from professional researchers and can be inclusive of people of any age or identity' (Nind, 2014, p. 6). I could have adopted this term as it is indeed an inclusive term. However, later in this thesis I discuss 'co-production' and I wanted to

use language which was perhaps terminologically more closely aligned to this. One research project where older people were involved wrote eight principles of co-production. These included involving people throughout, people feeling safe to speak out, working on issues that are important to those involved, and using people's skills to achieve change, (Bowers and Wilkins, 2012, p. 116). These principles are relevant to this research and sum up the way we worked together. The term 'co-researcher' seems more aligned to the term 'co-production' than any other term I am aware of. I also knew that many writers have also chosen to use the term 'co-researcher', for example in a research project involving older people (Ward and Gahagan, 2012). I am aware that there was a power differential between myself and the co-researchers so it did not seem accurate to use the same term for myself and the co-researchers. I fully recognise that I had the idea for the research, and set the tone for how we worked together. I chose to work in as enabling a way as I could, but I could have acted differently. The term 'co-researcher' did seem to be the best term that I was aware of that gave the co-researchers the status of being researchers, allowed for the difference between their role and that of a researcher and aligned itself to co-production.

## **Scope of the Literature Review**

The first four chapters of my thesis constitute the Literature Review. They will explore the concepts that informed my research as well as the underpinning philosophy. In the introduction I set out my aim to conduct participatory research with adults with Asperger's syndrome to determine what they thought about the support that they needed. In order to be able to achieve this I needed to enhance my knowledge of the literature. It was my own learning needs that formed the scope of my Literature Review.

The further chapters of the Literature Review are:

Chapter One will discuss the literature concerning Asperger's syndrome and autism, their history, how the subject has been documented and characterised by academic writers, many of whom are medical professionals. This chapter will examine the spatial metaphors that are used by neuro-typical writers when they write about autism and Asperger's syndrome.

Chapter Two will explore the literature that informed my research through a discussion of the concept of space. It will outline why I chose this concept to inform and frame my research. It will explore how the literature uses the concept, particularly Foucault and then critically compare this to an understanding of the literature written by people with autism about autism and Asperger's syndrome. It will conclude with a discussion of how the literature informed my research method.

Chapter Three will discuss the social model of disability, examining the context in which it arose, its criticisms and its application to this research. It will explore the difference between the personal and collective experience of disabled people and the importance of understanding the difference between disability and impairment. It will use the concept of space to discuss the way disabled people have been 'othered' by society and ways in which they want to be included. It will relate the messages from the literature to my research and how it informed the research method.

Chapter Four will discuss participation and participatory research. Part one of this chapter will discuss examples of participation and involvement in service and policy development, examine the concept of a participatory space, the motivation for creating one and how service users experience a participatory space. The second part of the chapter will examine participatory, emancipatory and co-produced research and discuss these concepts using spatial metaphors. It will also discuss the concept of an interrupted space and relate this to the discussion on the type of research space I

aimed to co-create with the co-researchers. The chapter will conclude with the implications for the research of the learning from the Literature Review, which in turn will lead on to the methodology section of the thesis.

# **Chapter One**

## **Literature Review I: Asperger's Syndrome**

In order to address the objectives identified for the research in the introduction, it was necessary for me to have an understanding of what Asperger's syndrome is as understood by professionals and by those who have Asperger's syndrome. I needed to understand how to work with a group of adults with Asperger's syndrome in a way which was what I thought of at the time as 'autistic friendly.' My review of the literature has led me away from this term and instead to think of 'autistic spaces' as opposed to 'neuro-typical spaces'. The work of Foucault and Hacking in particular led me to consider the different types of spaces that people inhabit (this is considered in Chapter Two). As I read the literature about Asperger's syndrome and autism written by clinicians and researchers as well as by those with the diagnosis, I was struck by how much of the literature used spatial metaphors. This chapter will discuss how the literature informed my understanding of Asperger's syndrome which in turn informed every aspect of the research project. I will examine what the literature constitutes autism and Asperger's syndrome, what their diagnostic criteria are, what causes autism and Asperger's syndrome and how the way autism is understood frames the way people with the two conditions are treated. Much of this literature has a medical orientation and whilst I do not want to adopt the deficit stance taken in this literature I did want to gain an understanding of how autistic people are regarded. I also wanted to identify any differences between autistic people and myself as a neuro-typical person that I would need to consider in planning how to conduct my research. I will conclude by examining the implications of the literature for my research.

### **1. Setting the context for the discussion**

Asperger's syndrome as a distinct syndrome has a fairly short but hotly debated history. During the period in which this research took place, Asperger's syndrome has been dropped from the psychiatrists' Diagnostic and Statistical Manual (DMS-5) and

merged with the wider category of 'autism spectrum disorder'. This was proposed to take effect from May 2013 (Guardian.co.uk, 2012). The implications of this are uncertain and will stretch beyond the writing of this thesis. Questions remain about how long Asperger's syndrome will be recognised in the UK as a distinct category within autism. (I will use the term 'Asperger's syndrome' throughout this thesis as it is still in current use in the UK at the time of writing and my research commenced before any re-categorisation.) This important development sets the context for considering how categories of disability are constituted by professionals and also it seems, reconstituted. My view, as informed particularly by my reading of Foucault, is that powerful professionals, especially medical professionals make observations about people based on what they consider to be 'normal' development and behaviour.

'Differences' are perceived but rather than these being seen as characteristics of some individuals within the 'normal' range, they are seen as deficits and so have become the subject of professional judgments and theorising (Oliver, 2009). I do not deny that there are differences in how some people think and understand communication but I think that these are differences rather than deficits. The characteristics of people with Asperger's syndrome are experienced as problematic for them because they are misunderstood and have to try and live in and fit into a world which is dominated by people who do not have autism and are regarded as 'neuro-typical'. In order to see how Asperger's syndrome has been constructed and understood a brief historical account will be undertaken. I do not intend to go into any great detail about the more medical aspects of diagnosis as this is beyond the scope of this thesis, but I will note some of the debates that have taken place between clinicians and researchers. Much of the literature about autism and Asperger's syndrome alludes to or specifically addresses the relationship that people with the two 'conditions' have to the world of neuro-typicals (Hawkins, 2004; Attwood, 2007). Some of the literature characterises people with autism as being 'in a different world' and people with Asperger's syndrome as being 'in the world', but unable to relate to it or to the people in it (Happé, 1994). Some literature discusses how people with Asperger's syndrome have

not developed the same cognitive skills as neuro-typical people to enable them to function in the same way (Happé, 1994, Baron-Cohen, 1997). Other literature talks about people with autism and Asperger's syndrome as seeming to be from a different world (Asperger, 1991). This 'othering' of people with Asperger's syndrome and autism is not just the province of neuro-typical writers; it is a theme in the literature, particularly the autobiographical literature written by people with Asperger's syndrome themselves (Barnhill, 2007; Muggleton, 2012). This separation of people into two main types, those with autism or Asperger's syndrome and neuro-typical people is a common theme that unite the literature. An exploration of how autism is perceived will explain why people with autism are regarded, by themselves as well as by neuro-typical people, as being different.

## **2. What is autism/Asperger's syndrome?**

The account of how Asperger's syndrome came to be recognized has to be considered alongside an account of autism as the two are related and discussions about their relationship continue. I will refer to both as the literature does this, making it difficult to separate discussions of the two. Both autism and Asperger's syndrome were proposed as deviations from 'normal' development based on observations of behaviour and in particular the way children related to other children as well as to adults (Kanner, 1946; Asperger, 1991; Attwood, 2007). The understanding of what was thought to be 'normal' behaviour and development was and is the axiomatic assumption here. The very use of the word 'syndrome' indicates this. The Collins English Dictionary (2003) defines a syndrome as: 'a combination of signs or symptoms that are indicative of a particular disease or disorder'.

The brief historical overview below will show how clinicians and researchers came to understand that some children and adults function differently from others. Early writers proposed autism and Asperger's syndrome as two categories in which to place them. This formalised and 'medicalised' the differences which were observed, with a body of knowledge and whole careers growing up around these categories.

The early literature concerning Asperger's syndrome and autism is concerned with children rather than adults. This is because early studies (Kanner, 1946; Asperger, 1991) were concerned with the developmental differences observed in children. As both Asperger's syndrome and autism are said to be lifelong conditions (Happé, 1994), the theorising in relation to children is also applicable to adults.

#### **a) Asperger and Kanner**

The main development in the formulation of the concepts of autism and Asperger's syndrome as conditions or 'syndromes' came with the publications of Kanner and Asperger in the 1940s. Hans Asperger's paper 'Autistic psychopathy' was published in 1944 but was not available in English until 1991 when Frith (1991) translated it from the German and included it as a chapter in her book on 'Autism and Asperger Syndrome.' Asperger's paper presents case studies of children who he had seen in his clinic. In his introduction, Asperger refers to these as a:

...type of child ...(who) all have in common a functional disturbance which manifests itself in their physical appearance, expressive functions and, indeed, their whole behaviour (Asperger, 1991 p. 37).

According to Asperger, this 'disturbance results in severe and characteristic difficulties in social integration' (Asperger, 1991, p. 37). Asperger refers to the characteristics that he observed in these children as a 'personality disorder'. He explains:

I chose the label autism in an effort to define the basic disorder that generates the abnormal personality structure of the children we are concerned with here (Asperger, 1991, p. 38).

Asperger explains that he uses the word 'autism' as the 'autist is only himself (sic)...and is not an active member of a greater organism which he is influenced by and which he influences constantly' (Asperger, 1991, p. 38). Asperger compares autism to



schizophrenia and declares that the common denominator is 'the shutting-off of relations between self and the outside world' (Asperger, 1991, p. 39). When describing the behaviour of the children in his case studies, Asperger uses words such as 'deviant' (Asperger, 1991, p. 39), 'malicious' (Asperger, 1991, p. 43), 'child prodigies and...imbeciles' (Asperger, 1991, p. 46) and 'naughty and aggressive' (Asperger, 1991, p. 47). His description paints a picture of children who may be very intelligent but who find difficulty in accessing formal learning and are very difficult to teach due to their disruptive behaviour. They do not relate to other children, do not show emotions to their family members but can inappropriately hug other adults, are sometimes cruel and are often the subject of bullying and teasing due to their appearance, presentation and inability to understand jokes. When referring to one child, Asperger states: 'He clearly did not have any feelings for the fact that he did not fit into this world' (Asperger, 1991, p. 66).

Asperger also traces the success of some children he observed into their adulthood and concludes that they were able to be successful in their work lives as they had unusual focus and talents in specific areas. For this reason, he concludes that 'autistic people have their place in the organism of the social community' (Asperger, 1991, p. 89).

As Asperger's paper was not translated and published in English until 1991, it was not widely known in Britain. What was known as Kanner's autism was the focus of attention until the 1990s. The year before Asperger wrote his paper, Kanner (1943) published his paper, which again is an account of the behaviour and presentation of children. He called what he saw as a pattern in this behaviour 'early infantile autism'. Kanner and Asperger used the term 'autism' independently of each other and it seems without knowledge of each other's work. Asperger explains that he uses the term autism as first used by Bleuler to describe someone who has limited interaction. The word is derived from the Greek word *αυτος* (autos) meaning 'self' (Asperger, 1991, p. 38). Kanner begins his paper: 'Since 1938, there have come to our attention a number

of children whose condition differs so markedly and uniquely from anything reported so far, that each case merits...a detailed consideration of its peculiarities' (Kanner, 1943, p. 217).

From these 'peculiarities' Kanner in a later work with Eisberg in 1956 developed five diagnostic criteria for autism:

1. A profound lack of affective contact with other people
2. An anxiously obsessive desire for the preservation of sameness.
3. 'A fascination for objects...
4. Mutism, or a kind of language that does not seem intended to serve interpersonal communication.
5. The retention of an intelligent and pensive physiognomy and good cognitive potential manifested, in those who can speak, by feats of memory...' (cited in Wing, 1991, pp. 93-94).

Wing highlights the similarities and differences between Asperger's and Kanner's account of the children they studied. The similarities include 'social isolation, egocentricity and lack of interest in the feelings or ideas of others', 'the lack of the use of language for interchange with others', 'impaired non-verbal aspects of communication...including poor eye contact', 'a lack of flexible imaginative play', 'dislike of environmental change' and 'special abilities, in contrast to learning problems in other areas' (Wing, 1991, pp. 93-94). Wing lists the main difference between the two papers as being the characteristics that Asperger noted including the fact that speech had developed before school age in the children that he observed and that there was a tendency to talk 'like grown-ups' in early childhood. Also, the children that Asperger noted were socially isolated, as were Kanner's, but they were not unaware of the existence of others around them. However, Kanner (1943), when talking of the fact that the children took no notice of the adults in his office when they came to be examined, states: 'It would be wrong to say that they were not aware of

the presence of persons. But the people, so long as they left the child alone, figured in about the same manner as did the desk, the bookshelf, or the filing cabinet' (Kanner, 1943, p. 246).

The children in Asperger's account also showed 'originality of thought', and interests which were 'canalised into rather abstract subjects of little practical use' (Wing, 1991, pp. 96-97). Kanner did not only report on what he observed, but like Asperger, he made judgments about it. In his case study on 'Paul', he relates various phrases that Paul used but concludes: 'None of these remarks was meant to have communication value. There was, on his side, no affective tie to people. He behaved as if people as such did not matter or even exist' (Kanner, 1943, p. 228).

Asperger and Kanner both seem to conclude that the children they observed not only are unable to relate in a meaningful way to others, but also have no motivation or inclination to do so. Kanner believed that the characteristics that he observed 'form a unique 'syndrome'' (Kanner, 1943, p. 242). He states: 'The outstanding 'pathognomonic' fundamental disorder is the children's *inability to relate themselves* in the ordinary way to people and situations from the beginning of life' (Kanner, 1943, p. 242).

#### **b) Asperger's syndrome as distinct from Kanner's autism**

Drawing on Asperger's paper, Wing (1981) proposed the term 'Asperger's syndrome' to describe a syndrome distinct from Kanner's autism. Wing brought Asperger's work to the attention of the English speaking world (Happé, 1994), it being largely unknown as it was not translated for another ten years into English (as noted, it was translated into English by Frith and published in 1991). In her paper, Wing describes 34 cases of children with autism who were a better match to Asperger's rather than Kanner's descriptions. The children which Asperger and Kanner describe had in common 'social impairment' and 'displayed poor eye contact, stereotypical behaviour, resistance to change and circumscribed special interests' (Kugler, 1998, p. 13). Their differences lay

in part in language abilities, with the children Kanner described having 'profound language delays and difficulties' and the ones Asperger described had 'fluent speech with rapid mastery of a formal language system'. Other differences concerned motor skills where Kanner thought the children he observed tended towards 'rote learning' whereas Asperger thought the children he observed showed originality and spontaneity of thought (Kugler, 1998, p. 13). After Wing's paper, interest grew amongst British and Swedish psychologists and psychiatrists and in 1988 a conference was held in London to explore this recent development in the understanding of autism. From the discussions and papers delivered at this conference, the Gillberg diagnostic criteria was published, which was the first diagnostic criteria for Asperger's syndrome (Attwood, 2007). The Gillberg diagnostic criteria consists of a list of features under the following headings:

1. Social impairment
2. Narrow interest
3. Compulsive need for introducing routines and interests
4. Speech and language peculiarities
5. Non-verbal communication problems
6. Motor clumsiness

(cited in Attwood, 2007, p. 37).

Attwood (2007), a practicing clinical psychologist, states that he uses Gillberg's criteria in his clinical work in preference to other criteria which have been devised since. The first criterion of 'social impairment' should be met and a selection of the others in order to confirm a diagnosis of Asperger's syndrome. This shows the primacy that is given to social competence and highlights the subjective nature of diagnosis as the judgment about whether someone meets the criteria or not is determined by the experience of the clinician (Attwood, 2007). This can obviously vary from clinician to clinician and can only be based on their own assessment of what is social competence and hence impairment in this area. This makes diagnosis of autism/Asperger's syndrome quite different from a disease where, for example blood tests or scans can

determine the outcome. Not only are the criteria based on professionals' views of what is 'normal' or 'competent', but the interpretation and application of the criteria is also based on individual professional views. Clinicians are given (or take on) the role of arbiters of normality. This gives clinicians a very powerful role not just with individuals where the diagnosis they receive can have a great impact on the whole of their lives, but also in relation to determining what is 'normal' and what is not in a society where difference is not always viewed positively. Clinicians thus become arbiters of normality, a criticism which was levelled against psychiatrists in the 1960s and 1970s in relation to 'madness' (Coppock and Hopton, 2000).

Wing details the debate amongst clinicians about whether the syndromes that Asperger and Kanner describe are different or related to each other. This debate demonstrates how both syndromes are regarded as outside of 'normality' and even portrays children with autism and Asperger's syndrome as being from a 'different world'. Wing cites Van Krevelen, writing in 1971 who believed that the two were 'entirely different' but related to each other (Wing, 1991, p 99). Van Krevelen believed that the main difference between children with Asperger's syndrome (which he called 'Autistic Psychopathy') and autism is that of the child's attitude to others. Children with autism behave as if they are unaware of others, whereas children with Asperger's syndrome show an awareness of other children, but avoid them (Happé, 1994). Happé characterises Van Krevelen's differences as being that the child with early infantile autism (Kanner's autism) 'lives in a world of his (sic) own' whereas the child with autistic psychopathy 'lives in our world in his own way' (Happé, 1994, p. 93). The notion of separateness is really emphasised here. The suggestion is that although the child with Asperger's syndrome is in 'our world' (presumably that of neuro-typical people), unlike those with autism, they inhabit it in a different way to other people as it is not really 'their world'.

### **c) Criteria used in the diagnosis of autism and Asperger's syndrome**

### **i) Characteristics of autism and Asperger's syndrome seen as outside of 'normal' development**

Debate continued over the relationship between Asperger's syndrome and autism but all literature seems to agree that they both describe individuals who are outside of the 'normal' range of social and communication development. Asperger's syndrome was included in the formal diagnostic manuals DSM-IV (American Psychiatric Association, 1994) and that of the World Health Organization but Kugler (1998) comments that this was controversial as some clinicians and researchers believed that Asperger's syndrome is really a form of 'high functioning autism' and others did not agree with the criteria given for diagnosis. Kugler comments that the inclusion of Asperger's syndrome within the 'pervasive developmental disorder classification' has been helpful as it has differentiated it from 'quite different abnormalities in social functioning' (Kugler, 1998, pp. 12-13). The language employed for the categorisation of 'pervasive developmental disorder' indicates that individuals who are diagnosed with Asperger's syndrome have developed in a way that is not normal and have a 'disorder' that pervades their whole being. Kugler also states that diagnosis of both autism and Asperger's syndrome is based on 'behavioural descriptions of symptom clusters, with diagnosis entailing subjective judgments of whether behaviours are normal or clinically abnormal, qualitatively the same or different' (Kugler, 1998, p. 13). Assumptions about what is normal and how this is formulated are made by clinicians who have devised the criteria. These are then further interpreted by other clinicians when they diagnose individuals.

### **ii) Classification of Asperger's syndrome**

Since Kanner and Asperger's papers, various studies have taken place and papers subsequently written which debate the nature of and relationship between autism and Asperger's syndrome (Wing, 1991; Kugler, 1998). Kugler details the debate about the nature of Asperger's syndrome and concludes that it should remain within the classification of autistic spectrum or pervasive developmental disorders 'with the *social impairment* acknowledged as primary' (Kugler, 1998, p. 24).

One of the World Health Organisation (1993) diagnostic criteria is: '...qualitative abnormalities in reciprocal social interaction (criteria as for autism)' (F84.5, B).

This is alongside 'normal' speech development, 'self help' skills and curiosity about the environment consistent with 'normal development' during a child's first three years, possible delayed motor milestones and 'isolated special skills' (F84.5, A). Also, to meet the criteria, the individual would display 'unusually intense, circumscribed interest or restricted, repetitive and stereotyped patterns of behaviour, interests and activities' (F84.5, C) and this would be the same as the criteria for autism but would not include 'motor mannerisms' or 'pre-occupation with part-objects or non-functional elements of play materials.'

Whilst, as indicated above, there has been much academic debate over the relationship between autism and Asperger's syndrome, Wing (1991) proposed that the most helpful way of overcoming this is to think of an autistic spectrum or 'autistic continuum'.

#### **d) The Triad of impairment**

Wing (1991) proposed the 'triad of impairment' to capture the overarching features of those individuals with autism and Asperger's syndrome. The triad consists of impairments 'in the skills of social interaction, communication and imagination' (Wing, 1991, p. 115). Wing also emphasises that there are other variables to consider in any diagnosis such as language usage and reading and writing. The triad of impairment is the model that in my experience as a social work practitioner is the widely accepted way of understanding both autism and Asperger's syndrome. It is by definition a deficit model. The acceptance of this model in understanding autism is demonstrated by the discussion of it in the report of the task group on autism, commissioned by Department of Education and Science (2001). The report describes Wing's work as 'One of the most significant contributions to the clinical understanding of autism as a spectrum disorder' (ch. 2, p. 2). The report then described the triad of impairment and

bases the understanding of autism it outlines on the triad. The philosophy behind this report is revealed in the very telling sentence: 'Sadly, there is no known cure for autism but appropriate support and education in the early years can greatly improve later functioning...' (p. 15, 2.7).

The National Autistic Society's website uses the triad of impairment to define Asperger's syndrome and proposes it as a model for parents to understand their autistic child. It also suggests that it is used as the basis for developing strategies for children with Asperger's syndrome in the classroom. The same website also uses the triad of impairment as the basis of information for other professionals working with people with autism and Asperger's syndrome. The website defines the autistic spectrum using the triad of impairment: 'The whole spectrum is defined by the presence of impairments affecting social interaction, communication and imagination. This is known as the triad of impairments. This is always accompanied by a narrow repetitive range of activities' (National Autistic Society, n.d.). It defines the characteristics as detailed in the triad as being:

1. Social interaction- **Problems engaging in reciprocal social interactions**

A severely affected individual will seem aloof and uninterested in people where someone less affected (but still affected) passively accepts social contact, even showing some pleasure in it, though he/she does not make spontaneous approaches.

2. Social communication- **A lack of appreciation of the social uses and the pleasure of communication is always present in some form or other**

A significant proportion of people with classic autism fail to develop useful speech. If language is used, there is a failure to understand that it is a tool for conveying information to others. Some ask for their own needs but have difficulty in talking about feelings or thoughts and in understanding the emotions, ideas and beliefs of other people.



3. Social imagination- **Inability to play imaginatively with objects or toys or other children/adults**

Pretend play can be absent or repetitive. A tendency to select for attention minor or trivial aspects of things in the environment instead of an imaginative understanding of the meaning of the whole scene is often found. Some imaginative activities may be displayed but these are usually copied, for example from TV programmes. This play may seem complex, but careful observation shows its rigidity and stereotyped nature ([www.autism.org.uk](http://www.autism.org.uk)).

The website demonstrates the general acceptance of the triad of impairment. The National Autistic Society is often consulted by people with Asperger's syndrome or autism as well as by family members and professionals. I have attended many training sessions on autism in my role as a social work practitioner and the triad of impairment has been used on every occasion as the accepted way of understanding autism/Asperger's syndrome.

The triad of impairment is the primary way in which professionals comprehend Asperger's syndrome. From a different perspective, Bogdashina (2006) highlights that although the triad of impairment may be useful in recognising autism 'from the outside' it has also brought with it the view that the three impairments are 'inabilities' to interact, communicate and imagine'. She proposes that if viewed as being a 'fundamentally different way of being' then the same behaviours can be viewed more positively (Bogdashina, 2006, p. 81). This view is more in line with the view I took in this research as will be explored later in this chapter.

The triad of impairment demonstrates why people with Asperger's syndrome and autism are thought by clinicians not to fit into the neuro-typical world. It was developed to describe the 'deficits' of people with autism and as such does not allow for the possibility of another way of 'being' in the neuro-typical world that is not based on a deficit model. Implicit in the triad of impairment is that some people are found to

be lacking in what are considered to be normal ways of thinking, communicating and behaving.

### **3. Explanations of autism and Asperger's syndrome**

Various theories concerned with why some people are autistic have been proposed since Kanner's and Asperger's writing. I will discuss what the literature says about three of these theories and then consider the implication of them for people with Asperger's syndrome and their carers. I initially chose these particular theories because I had been introduced to them in training courses when I was a social work practitioner. I wanted to re-visit them as they had shaped the way I thought about Asperger's syndrome and I wanted to take the opportunity to reflect on them.

#### **a) Theory of Mind and 'Mindblindness'**

One way of describing autism is through the concept of 'mindblindness' or a lack or deficit in ability to 'mindread'. Baron-Cohen (1997) states that in 1985, he, Frith and Leslie proposed that 'three of the cardinal symptoms in autism-abnormalities in social development, in communication, development, and in pretend play- might be the results of a failure in the development of mindreading' (Baron-Cohen, 1997, p. 63). Theory of Mind (ToM) refers to the ability of people to make sense of the behaviour of others through an understanding of what they are thinking. It includes the ability to predict what people might do next (Attwood, 2007). The lack of ability to do this is often referred to as 'mindblindness' (Baron-Cohen, 1990; 1997). Baron-Cohen coined the term when he was describing autism (Baron-Cohen, 1990). People with autism and Asperger's syndrome are said to lack ToM. This has given rise to people with Asperger's syndrome being said to lack empathy (Gillberg, 2002) as people with Asperger's syndrome are thought to have difficulty understanding the cues which indicate what another person is feeling or thinking (Attwood, 2007).

Much of the literature refers to the fact that people need to be able to 'mindread' in order to understand social situations (Happé, 1994; Attwood, 2007). A lack or a deficit

of mindreading results in an individual misunderstanding others and often being regarded as 'odd' by other people (Baron-Cohen, 1997; Attwood, 2007). Baron-Cohen reveals how 'unfortunate' he thinks it is that people with autism are mindblind when he says: 'Tragically, mindblindness is not an idle thought experiment or a piece of science fiction' (Baron-Cohen, 1997, p. 5). Baron-Cohen explains that it is evolutionary psychology that has informed this approach. Evolutionary psychology, as Baron-Cohen explains is: 'psychology informed by the fact that the inherited architecture of the human mind is the product of the evolutionary process' (Baron-Cohen, 1997, p. 9).

Evolutionary psychology examines the brain and takes as a premise that through natural selection the brain has evolved specific mechanisms to solve particular adaptive problems. So, through the process of evolution, one of the mechanisms that humans developed was 'mindreading' so we can predict the behaviour of others, even in the absence of behavioural cues. Baron-Cohen states that humans are probably born with this ability and it is used for 'social understanding, behavioural prediction, social interaction and communication' (Baron-Cohen, 1997, p. 30). Baron-Cohen states that there are four stages in 'mindreading', one of which is the Theory of Mind Mechanism (TOMM). As he explains, 'This includes representing the set of *epistemic states* (which include pretending, thinking, knowing, believing, imagining, guessing, and deceiving)' (Baron-Cohen, 1997, p. 51).

Baron-Cohen states that children with autism also have 'massive impairments' in SAM (Shared –Attention Mechanism), which is another aspect of mindreading. SAM is concerned with the recognition of self and of others and relationships to objects. According to Baron-Cohen, the central purpose of SAM is to establish when an object is of shared interest with self and another person. He theorises that a lack of SAM may be why children with autism do not use a range of intonation in their speech as they lack the concept of an 'interested listener' (Baron-Cohen, 1997, p. 69).

According to Happé (1994) people with Asperger's syndrome do not possess Theory of Mind in early childhood, but do develop it 'not unlike a normal child's-due to internal or external factors' (Happé, 1994, p. 98). (Happé's choice of the word 'normal' does indicate a position about 'normality' which I do not share). However, because the development is late, it will have missed the 'critical period' and so it is too late to develop a 'normal' Theory of Mind. Instead, the person with Asperger's syndrome is left with a deficient Theory of Mind that will not 'allow them to solve the more subtle Theory of Mind problems encountered in everyday situations. Thus, they will fail to apply their hard-won Theory of Mind skills in real life' (Happé, 1994, p. 99).

The evolutionary basis of the Theory of Mind explanation of autism and Asperger's syndrome takes the metaphor away from the suggestion that people with those diagnoses are of a different world to a less abstract and seemingly more scientific explanation which is that they somehow got left behind by evolution. People with Asperger's syndrome are just not equipped to understand others and so are bound to fail socially.

### ***Criticisms of Theory of Mind***

Hacking gave a presentation at a conference where he detailed his critique of Theory of Mind, disputing the assumptions behind it of human behaviour being based on a 'double edged notion'. This talk is discussed in a blog following the conference (Ronamundson, 2009). The first notion is that human behaviour is based on 'internal, language-like inferential structures in the brain' and the second is that humans internalise 'that other humans have the same kind of language-like structures that we ourselves use in reasoning about the world' (Ronamundson, 2009). He rejects the concept of Theory of Mind in general, not just as it applies to people with autism. Hacking (2009) proposes an alternative view, the Wittgensteinian Form-of-Life theory of language and social knowledge. Hacking proposes that neuro-typical people 'intuitively and directly see people's intentions' rather than '*infer*' them from

behaviour as Theory of Mind proposes. The understanding of other people's intentions is a matter of *practice* rather than *theory* (Ronamundson, 2009).

Baron-Cohen (2008) himself criticises Theory of Mind and states that many people with autism report that they are unsure about how they should respond to another person's emotions. It is not just that they do not understand what the other individual is thinking, they do not know how to respond emotionally to that person's emotions, which as Baron-Cohen asserts, is another aspect of empathy. He also states that Theory of Mind can only account for social aspects of autism. Other characteristics which Theory of Mind does not account for are the tendency to systematise elements of the environment and having 'special interests' to an excessive level when compared to someone who is not autistic.

The possession of empathy is closely tied up with Theory of Mind as it is difficult to empathise with another person when there is a deficit in mindreading. Whether or not people with autism/Asperger's syndrome have empathy is discussed by Bogdashina (2006). She refutes that people with autism lack empathy. She proposes that people with autism experience their autism differently, depending on the support, strategies and adaptations that they receive:

...sometimes it may feel comfortable, and at other times it may be very frustrating. In contrast to official definitions of autism as outer behaviours (the more 'bizarre' behaviours the person exhibits, the more severe the autism is seen to be), for autistic people autism is inner reality and it can appear (on the surface), disappear and reappear in varying degrees in different circumstances (Bogdashina, 2006, p. 79).

#### **b) Extreme male brain**

There is a change of tone in Baron-Cohen's later work on autism where he emphasises the value of people with autism. In his more recent work (Baron-Cohen, 2004; Baron-

Cohen 2008), his stance seems to have changed from that of believing people with autism are not mentally equipped to function in the world, to society not being accepting of and valuing their differences. He develops his original Theory of Mind and proposes that autism is a form of 'extreme male brain' (Baron-Cohen, 2004). He uses the concepts of male and female brains as ways of discussing psychological profiles. These profiles were based on research where groups of men and women were tested for their abilities in empathising and systemizing. The 'female' brain is associated with empathising and the 'male' brain with systemizing. Baron-Cohen identifies three types of people; those with male brains, those with female brains and those with balanced brains, who are good at both empathising and systemizing. These types of brain are not always linked with gender as males can have female brains and vice versa. Baron-Cohen links difficulties with Theory of Mind with having a 'male' brain. He states that society is more accepting of people with female brains and stigmatises people with male brains. People with female brains do not feel that they have to hide their 'systemblindness' as this is accepted by society whereas those with 'mindblindness' do feel stigmatised so are inclined to hide this from society.

Baron-Cohen cites a young man with Asperger's syndrome (AS), 'People with AS are like salt-water fish who are forced to live in fresh water. We're fine if you put us in the right environment. When the person with AS and the environment *match*, the problems go away and we can thrive. When they don't match, we seem disabled' (Baron-Cohen, 2004, p. 180).

(In the next chapter I will explore the literature written by people with autism and show that this feeling of being from a different environment or world is a common theme. It was this quotation from Baron-Cohen, together with my reading of Foucault that started my thinking of the experience of people with autism in spatial terms. There are strong resonances here to the social model of disability, which will be discussed in Chapter Three.)

### **c) Weak central coherence theory**

One of the criticisms of Theory of Mind is that it does not account for 'non social' features (Baron-Cohen, 2008). To try and explain these features, Uta Frith proposed weak central coherence theory (Frith, 2003). Frith's position is that autism is 'a disorder of the developing mind and brain' and she writes of 'the likely genetic abnormality, the likely anatomical fault' and 'the likely physiological dysfunction that gives rise to autism' (Frith, 2003, p. viii). Her choice of the word 'weak' is indicative of her stance of autism as being deficit. Having said that, the theory does focus on the differences of autism, in terms of both strengths and weaknesses. Frith proposes that in a 'normal' cognitive system there is 'a built-in propensity to form coherence over as wide a range of stimuli as possible, and to generalize over as wide a range of contexts as possible' (Frith, 2003, pp. 159-160). In this theory, people with autism have an impairment in this ability and are not able to integrate information holistically. This is said to account for the abilities of people with autism to focus on very specific areas of information as well as their inability to understand wider contexts. Happé supported this theory and proposed that central coherence is a continuum with people with autism being at the 'weakest' end (Happé, 1999; Bogdashina, 2006).

## **4. Implications of causal explanations of autism for people with Asperger's syndrome and their carers**

There is a great degree of consensus about the clusters of behaviours which are likely to lead to a diagnosis of autism/Asperger's syndrome but far less about the causes. The theories of what causes autism have led to some very different approaches from professionals working with people with autism. The literature has demonstrated how influential the understanding of the causes of autism have been for professionals and the impact the different understandings have had for people with autism as well as their parents and carers. This is significant for my research as it explains why people with Asperger's syndrome have been regarded and subsequently 'treated' as they have. It explains the context for research which is seeking to ascertain how people with Asperger's themselves want to be supported. A medically based view tends to

lead to the concept of 'treatments' and concentrates on the person with autism (Lovaas, 1993). A psychologically based view which takes account of the environment, particularly the care given by parents or caregivers, has led to a focus of the care giver as causing autism through inadequate parenting (Whitman, 2004). An evolutionary psychological view sees the person with autism as not having developed adaptations to the social environment in the way that other people have (Happé, 1994; Baron-Cohen, 1997). Some views, such as the weak central coherence (Frith, 2003) and the extreme male brain theories (Baron-Cohen, 2004) also emphasise the strengths of people with autism. Baron-Cohen in discussing the extreme male brain theory, emphasises the role that society has in accepting differences and valuing strengths.

Some theories of the causes of autism have been influenced by the personal experiences of the theorist. For example, Bettelheim believed that autism in children was due to environmental trauma and the 'aloofness' which they displayed as being caused by having 'refrigerator mothers'. Bettelheim had been a prisoner of war in a Nazi concentration camp and he had noted the results of these very harsh environmental factors on those who endured them. Whitman has theorized that this experience influenced the way Bettelheim understood autism as it heightened for him the importance of environment on well-being (Whitman, 2004, p. 18). Kanner also observed that the parents of autistic children appeared detached. Whitman points out that the historical context of the Second World War through which the two men lived explains why they viewed environmental factors as being so important.

Theorists using the environmental approach concluded that the difficulties that individuals with autism experienced in language usage were the result of the primary and causative characteristic of social withdrawal (Mesibov, Adams and Klinger 1997). However, this position was heavily criticised and clinicians became increasingly convinced by a more biological theory (Whitman, 2004).



The shift in understanding from environment as the cause to the characteristics being biologically determined meant a shift from looking at the causes within the environment to 'treatments'. Educational methods were developed such as 'Lovaas'. These methods were forms of behaviour modification. In an open letter to discuss the form of education that he had devised for autistic children, Lovaas calls it a 'therapeutic intervention' and an 'appropriate treatment' (Lovaas, 1993). This medicalised language of treatment is seen in other publications when referring to autism (Yapko, 1988).

Some clinicians, looking for a biological cause of autism proposed the possibility of viral causes. Chess' study concluded that some children's autism may have been caused by such a viral infection (Mesibov, Adams and Klinger, 1997). Other biological causes were examined, such as seizures, birth injuries and brain lesions (Tantam, 1991). The implications of a biological explanation were not in relation to how to 'treat' children or adults *for* their autism, but did have implications for choices that parents made on behalf of their children. Famously, claims in the media based on research by Andrew Wakefield, a gastroenterologist at the Royal Free Hospital in London that the MMR vaccine caused autism led many parents to choose not to have their children vaccinated (Adams, 2007). The claims have now been discredited (DeStefano and Thompson, 2004). However, the response of parents at the time partly is indicative of the population's view of the undesirability of autism. The preference was to risk children having measles, mumps or rubella than to risk giving them a vaccine which was alleged to cause autism. Kaufman (2009) refers to this as the 'vaccine-autism theory' and states that parents in the UK and USA were reluctant to believe that the claims of Wakefield were unfounded, even when his work was discredited and when further studies showed that there was no causal link between the vaccine and autism. This demonstrates the fear of parents of having a child with autism and this is a powerful example of some parents doing all they can to ensure that children are neuro-typical. The message to people with autism and Asperger's syndrome seems to be that it is not desirable to be autistic. The preference is for children to be of the

same world as neuro-typical people. In their discussion of eugenics, Roulstone and Prideaux (2012, p. 9) write 'The implications for those who fell way short of a new stereotyped image of normality and of 'fit' with society's needs was stark. A new science of categorisation had been born, one which could aid the more careful selection or eradication of those deemed unfit to live'. Although the MMR vaccination was not concerned with the 'right to live' or 'selection' as such, it has in common the unease of people being outside of this stereo-typed image of normality.

Attempts to prioritise avoiding having a child with autism over the risks associated with non-MMR vaccination is a clear indication of how some people in society view autism. Another indication is the development of behavioural techniques designed to change them. Lovaas stated 'One way to look at the job of helping autistic kids is to see it as a matter of constructing a person' (cited in Mesibov, Adams and Klinger 1997, p. 17). Mesibov, Adams and Klinger (1997) comment that this implied that the person with autism may be 'less of a person' and also that it is the role of the professional to change the person. Although Lovaas doesn't use spatial imagery, his work is based on a desire to change autistic children so that they become more acceptable to society and to fit in with a world in which they are strangers.

The way people with autism are treated does depend to some extent on autism's perceived aetiology. So, for Bettelheim, the logical approach would have been to work with the mothers and for Lovaas it was to apply behaviour modification techniques. When autism is understood from a medical perspective, the resulting language and experience of those with autism is that of treatment. These approaches are concerned with trying to make people with autism fit into the neuro-typical world. The literature and its review is informative as it demonstrates how much the understanding of autism affects the approach that is taken to working with autistic people.

## **5. Implications for research**

I have discussed how the literature demonstrates a 'medicalisation' of autism and a view of it as 'deviant' and as a pervasive developmental 'disorder'. It is understood in terms of a deficit in the ability to understand others and in communication.

Treatments have been proposed in response to different ways of understanding its causes. Some of the literature has viewed autism in a more balanced way, discussing the positives as well as the negatives. What the literature does seem consistent in is that people with autism and Asperger's syndrome are different from people who are neuro-typical. The explanations as to why this is, as we have seen does influence how people with these conditions are treated.

There is some agreement in the literature written by neuro-typical people that people with autism and Asperger's syndrome have difficulties in understanding what neuro-typical people are thinking as well as their behaviour. Whether they can be called 'mindblind' when people who are neuro-typical also cannot understand how people with autism think or understand their behaviour is an important point. If it was true that people with Asperger's syndrome are 'mindblind', it would have real implications for participatory research as it would question the ability of people with Asperger's syndrome to generalise and speak for anyone but themselves. If an inability to mindread means that it is difficult to understand social situations, then this would mean that asking a group of people with Asperger's syndrome to work together could be difficult. It also raises the question of how people with Asperger's syndrome could be involved in interpreting data, for example, when they do not have a concept of what other people think. However, I wanted to give people with Asperger's syndrome the opportunity to take part in all aspects of the research and felt that if I based my inclusion of them on the theory that they were 'mindblind', I could be in danger of excluding them from key aspects such as the data analysis. For this reason, I decided not to assume that the people in my group were incapable of contribution of any sort but instead sought to ask them about what were helpful ways of working together and optimising individual contributions. I wanted the co-researchers to be able to discuss

and apply their experiences to the research design. In relation to the difficulty that the co-researchers might have in understanding social situations, my approach was that we could create the social situation together and co-create it in such a way that it was understandable to all involved.

The triad of impairment also has significant implications for the research. I wanted to form a group which, for my research to succeed, would need to work well on fairly complex tasks. The individual members of the group would have to work well with each other as well as with me, a neuro-typical person. The triad of impairment details difficulties in communication, social interaction and imagination as detailed above. I had seen in the literature how a more medical understanding of autism had led to the view that autism needs to be 'treated'. I wanted my approach to working with the group of adults with Asperger's syndrome to be very different from that which is informed by a medical understanding. Bogdashina (2006, p.303) uses a metaphor of people with autism being like a fruit tree, with '...the roots spread very deep in the soil (different biological causes, unknown yet), a trunk (the same pattern of psychological development resulting in the similar symptoms), and branches and twigs (the uniqueness of each individual's features)'. She exhorts, 'It is in our power to let the tree blossom'.

In order to do this, she proposes an alternative triad, a triad of perspectives, with the three corners being autistic individuals, professionals and parents (Bogdashina, 2006). Bogdashina is stating that autistic people can 'blossom' if the conditions are right. She is referring to the combined working together of the autistic person, their parents and professionals. She writes that before society can change to 'create environmental conditions that make both autistic and non-autistic individuals comfortable' people must accept that individuals have different minds. She states that everyone has a lack of empathy or limited empathy as we do not understand each other. People who are neuro-typical do not understand people with autism so are just as lacking in empathy. Bogdashina's approach is one which I share and wanted to be at the heart of my

research. This emphasises the role of environment but not as a cause of autism as in earlier suggestions discussed in this chapter, but in the role of causing difficulties for people who have autism. For this research I had to think of co-creating an environment which not only did not create difficulties for people with Asperger's syndrome but provided a space for them to reflect on their own and the experiences of other people with Asperger's syndrome (this will be further developed in Chapter Four).

The literature has shown me much which I can express in terms of my spatial understanding of autism and Asperger's syndrome. I have learnt that people with Asperger's syndrome feel uncomfortable in the world of neuro-typicals. They do not understand the space they are placed in and can feel like a salt water fish in fresh water (to use Baron-Cohen's citation). They are regarded generally as having an inferior way of thinking and there have been attempts to make them fit more into the neuro-typical space they inhabit rather than amend the space. In common with Bogdashina, I also want the people I work with on the research to 'blossom'. I therefore need to create an environment with them that they are 'comfortable with' and one in which I am also 'comfortable'.

In the next chapter I will discuss what people with autism have written about having autism in the context of the concept of space. I will discuss how an examination of the literature on space helped to develop further the aspirations expressed in this chapter to create an environment in which a group of people with Asperger's syndrome could work together with me on the research. I will discuss how the application of the concept of space gave me a framework for challenging deficit-based views of Asperger's syndrome as well as suggesting ways of working positively with adults with Asperger's syndrome for this research.

## **Chapter Two**

### **Literature Review II: Asperger's syndrome and Space**

#### **1. The concept of space as a means of analysis**

As the previous chapter has shown, spatial imagery has been used by both neuro-typical and autistic writers to describe the differences between neuro-typical and autistic people. Other literature also used the concept of space to show how people are excluded by society (Foucault, 1977a; Foucault, 1988; Price-Chalita, 1994; Cornwall, 2004). I was intrigued by the potential of the concept to illuminate the experience of people who feel excluded as well as to account for the reasons for their exclusion theoretically. The literature on the concept of space influenced my research in two ways:

- i. It gave me a framework for challenging conventional, deficit based views of Asperger's syndrome
- ii. It gave me a framework for devising ways in which to work with people with Asperger's syndrome.

I will discuss participatory research in Chapter Four, but I want to mention here the work of Kindon, Pain and Kesby (2007) who discuss participatory research as spatial practice. They propose that conceiving of participatory research as spatial practice allows for a view of the arenas in which participation takes place as being governed by the 'discourses and practices of participation' (Kindon et al, 2007, p. 24). They also propose that the 'modalities' and spaces of power and empowerment are 'entangled' (Kindon et al, 2007, p. 23). These insights led me to see the potential of a spatial approach to understand how power and empowerment worked within research and so to address this in my research design as well as in the discussion of this research.

I have already acknowledged the influence of Foucault's work on the approach that I took to my research. In this chapter I will discuss how his writing influenced my own perceptions of people with Asperger's syndrome and what impact this had on my research. I will also apply the understanding of spatial analysis I gained from the wider literature about space to the literature written by people with Asperger's syndrome and autism about their condition. I will then say how I applied what I learnt from the literature to my research.

I chose to use the concept of 'space' as I believed from the literature that it would potentially give me insights into:

- How people with Asperger's syndrome are viewed by society.
- How they view themselves.
- How to form a group of adults with Asperger's syndrome to work with me in a participatory way on the research and
- What the participants of the research wanted from the services and support that they receive.

The first two points concern the understanding I gained from the literature written by people with Asperger's syndrome and their experience of living in a society which is dominated by neuro-typical people. Thinking of this literature using spatial metaphors provided me with the insights to challenge conventional, deficit based views of Asperger's syndrome. The third point concerns how the literature helped me to frame my research and form a group of adults with Asperger's syndrome in a way which was 'enabling'. My learning from the literature helped me avoid replication of the lack of understanding which people with Asperger's syndrome experience in society. The last point is concerned with data analysis and my aspiration to use the insights I gained from the literature about space to frame the results of the analysis. I have used insights from different writers to help frame my thinking around these points. The concept of space was therefore the main one that helped to frame the approach underpinning the research as well as help me frame the way the research should be conducted.

## **2. How the concept of space has been used in the literature**

Space has been a concept used by academics as a vehicle to discuss social issues. It builds on the commonly held understanding of space as physical space. The way in which physical space is divided up into smaller spaces may not be something that people consciously consider but they are familiar with it as physical space is divided up into fields, roads, housing estates and so forth. The ownership of physical spaces is also a familiar concept to people with the ownership of spaces affecting who can have access to them and what people are allowed to do in them, depending on their relationship to the space and its owner. The literature builds on these 'common sense' understandings of physical space to critique aspects of society. The change in the use of 'space' from a literal place to a more symbolic concept has been traced by Hubbard, Kitchen and Valentine (2004). They trace the history of the development of the concept of space in geography and describe how originally it was conceived as being 'straightforwardly empirical, objective and *mappable*.' Human geographers considered space to be 'a neutral container, a blank canvas that is filled with human activity' (Hubbard, Kitchen and Valentine, 2004 p. 4). From the 1970s a new concept of space evolved with geographers conceiving of space 'as a surface on which the relationships between (measurable) things were played out' (Kitchen and Valentine, 2004 p. 4). This new interpretation of spatiality was '...inherently caught up in social relations, both socially produced and consumed' (Hubbard, Kitchen and Valentine, 2004, pp. 4 - 5). The authors describe how urban sociologists joined geographers in using the concept to document processes such as urbanisation. Many theorists, who were not geographers, have since used this understanding of how space can be perceived in order to critique social and political phenomena. One of these theorists was Foucault, whose work had been cited by many other authors I had read at an early stage in my research and I will consider in the following section.

## **3. The concept of space and how it influenced the approach to the research**

### **a) Foucault - space and power**



In the previous chapter, I explored how the literature characterised people with Asperger's syndrome and autism as being essentially different from people who are neuro-typical. I examined the papers of Asperger and Kanner and detailed the language that they used to represent the 'differences' that they observed. I was attracted to the work of Foucault in relation to framing my thinking for this research for two main reasons, both of which relate to how people with Asperger's syndrome are viewed. Firstly, his understanding of power and how it is bound up with the production of knowledge and secondly how he illustrates this through his use of spatial analysis.

Foucault's use of spatial analysis challenged accepted ways of thinking and I wanted to extend this to perceptions of Asperger's syndrome. Spatial analysis was a significant element in much of Foucault's work and his spatialized thinking as an approach was 'core to his historical method'; it freed him from historical realism and allowed him to be free of the 'tangled network of influences', which might otherwise have shaped his work (Flynn, 1994, p. 41). I also wanted to step back from the dominant influence of the medically framed deficit model of people with Asperger's syndrome seen in the literature. I wanted to explore instead how people with Asperger's syndrome are characterised. I also wanted to use spatial insights to understand why people with Asperger's syndrome are characterised in the way that they are.

#### **a) Foucault's assertion that power operates through knowledge**

Foucault's work questions assumptions, beliefs and knowledge, 'It is precisely those aspects of our existence that seem closest to us, that seem the most obvious, the most certain, the most profound-that give us the deepest, most secure understanding of what we are-that become the object of genealogical history' (Barker, 1998, p. 23). For Foucault, power operates through knowledge. He proposed that different types of knowledge are produced by mechanisms of power. Knowledge is gathered about how people behave and this in turn reinforces exercises of power. Foucault does not claim that 'knowledge is power' but that there is a complex relationship between the two. It

is the exercise of power which leads to the 'emergence of objects of knowledge, bodies of transformation and the possible subjects that constitute themselves around them' (Barker, 1998, p. 27). The theoretical importance of this is that it challenges the belief that the 'subject' can understand truth 'from a politically neutral zone outside power' (Barker, 1998, p. 27). In applying this insight it is possible to question what the literature says about people with autism and to try and understand how the 'knowledge' about autism has led to power being exercised over them.

#### **a) Foucault and spatial analysis**

Foucault's work, according to Crampton and Elden (2007, p. 1) 'was always filled with implications and insights concerning spatiality'. Social scientists, as well as geographers and philosophers have 'either developed these issues in their own work, or through a sustained analysis of Foucault's own work'. Crampton and Elden characterise Foucault as a practitioner of 'spatial history' and one who developed his use of spatiality throughout his work.

It was Foucault's work together with the writings of others, particularly Cornwall (2004) who used Foucault's writing on space and power and applied it to participation, that suggested to me the possibility of using a spatial analysis to understand how people with Asperger's syndrome are treated in society. As Elden states,

...understanding how space is fundamental to the use of power and to historical research into the exercise of power allows us to recast Foucault's work not just as history but as a mapping of the present. (Elden, 2001, p. 152)

I was also attracted to Foucault's spatial analysis as implicit in it is the understanding that power is 'productive in relation to knowledge' (Barker, 1998, p. 25). In 'Lecture Two', given in 1976 Foucault states:

...in a society such as ours, but basically in any society, there are manifold relations of power which permeate, characterise and constitute the social

body, and these relations of power cannot themselves be established, consolidated nor implemented without the production, accumulation, circulation and functioning of a discourse...We are subjected to the production of truth through power and we cannot exercise power except through the production of truth (Foucault, 1980, p. 93).

The application of this insight to how power is exercised through discourse concerning autism was valuable to me as it enabled me to read the literature about autism in this light. I was enabled to perceive of the medicalisation of autism and Asperger's syndrome and the discourse produced to 'circulate' this discourse as the means by which they are subjects of power. Rather than read the literature produced about Asperger's syndrome as 'truth', I was able think about it as framing the differences between autistic people and neuro-typical people in terms of deficit.

I will now discuss other aspects of Foucault's work that influenced the way I thought about this research. I will discuss domains of thought and how this linked to the operation of power, spatial analysis and the concept of the 'Other', the gaze, disclosive spaces, criticisms of Foucault's view of power and lastly, the influence of Foucault.

#### **i) Domains of thought**

Foucault believed that society places constraints on people which make certain beliefs 'unthinkable' and the domains of thought which emerge as a result are contingent on each other. Every society shapes 'modes of thinking' that involve 'implicit rules' (Gutting, 2005, p. 33). For Foucault, archaeology is the process of discovering what these rules are; it is an analysis of the constraints on thought in society (Gutting, 2005, p. 47).

There is an 'intimate tie between knowledge and power' in Foucault's genealogies (Gutting, 2005, p. 50). It is social forces that change thought which in turn control the behaviour of individuals. For Foucault, power is bound up with knowledge rather than

each being totally identified with each other. Gutting explains Foucault's aim: 'His project is to question quite specific claims to cognitive authority: roughly, those made by psychologists and social scientists' (Gutting, 2005, p. 53).

The dominant domain of thought in relation to autism is that neuro-typical ways of thinking, communication and behaving are 'normal' and that people with autism deviate from these and so are impaired and in need of 'treatment'.

## **ii) Foucault's spatial analysis and the concept of the 'Other'**

Foucault used the concept of space as a vehicle for understanding how power operates through the separation of people into dualities. Philo (2004) details how Foucault:

Through his teasing out of how space 'works' in history, tracing the spatial configurations that expose how power operates in countless (mal)treatments of the 'unloved', he was seemingly able to throw into relief, to 'map', many of the questionable contours of the present (Philo, 2004, p. 124).

Philo (2004) describes how Foucault detailed the way society stigmatises groups of individuals through the duality of the 'Same' and the 'Other'. The 'Same' represents conformity to European norms and the 'Other' being the corollary of this, non conformity. Foucault documented a number of examples of the Other, including madness, criminality and sexual deviance. It is through the identification of the Other that the Same can define itself. Society, in this analysis has to have a group of people who it regards as different but in a negative way to legitimise the conformity of those who are not part of that other group. For Foucault, discourse and knowledge are essentially '...what a given society takes as the Same, as the accepted conventions for thought and action which incorporate both the leading statements of 'experts' ...and the more taken-for-granted assumptions figuring in the everyday lives of the populace' (Philo, 2004, p. 125).

Sarup (1993) summarises Foucault's view as 'knowledge is a power over others, the power to define others' (Sarup, 1993, p. 67). Power operates through the discourse which separates the Same from the Other. Professionals have the power to define people with autism and to characterise their differences as being a deficit. Foucault used physical spaces to analyse how people who are regarded as Other are treated. He discussed possible objects of thought which formed potential architectures, informing how people think in specific times. One example of this is his discussion of the Benthamite Panopticon as a form of control of prisoners which demonstrates how this could be used as a basis for surveillance and documentation. The panopticon was a design for a prison system where prisoners were separated into cells where they could not see other prisoners but where a central monitor could see them. Foucault believed its principles were used in institutions where power was exerted over others. Prisoners were not constantly monitored, but were unaware of when they were monitored so they behaved as if they were being monitored all of the time. The surveillance gave the opportunity to collect information about prisoners and by this means they became subjects of documentation. Foucault writes:

The overall aim was to make the prison a place for the constitution of a body of knowledge that would regulate the exercise of penitentiary practice. The prison has not only to know the decision of the judges and to apply it in terms of the established regulations: it has to extract unceasingly from the inmate a body of knowledge that will make it possible to transform the penal measure into a penitentiary operation; which will make of the penalty required by the offence a modification of the inmate that will be of use to society (Foucault, 1977a, pp. 250-251).

The physical space of the prison and specifically the panopticon is used to produce knowledge which in turn is used to control the offenders. Power is exerted over prisoners through this body of knowledge: 'It is as a convict, as a point of application for punitive mechanisms, that the offender is constituted himself (sic) as the object of possible knowledge' (Foucault, 1977, p. 252).

The panopticon represents the way in which society uses architecture to exert power through knowledge. The panopticon was not used but its importance was as an example of a possible mode of thought and a potential architecture. It served as both an example of a disciplinary regime and as a metaphor 'for the more diffuse operation of the disciplinary regime as a productive apparatus for Western culture in general' (Barker, 1998, p. 59). Foucault has used his detailed description of spatial organisation to analyse how prisoners are controlled and observed for the purpose of developing knowledge which in turn will then be used to further control prisoners. Although people with autism are not necessarily confined to a different physical space (unless they are in specialised residential care), they are characterised as belonging to another world. It is in the context of people belonging to this different world, to a different metaphorical space, that neuro-typical people can prescribe treatments.

### iii)      **The gaze**

Knowledge is also formed through 'the gaze'. Foucault starts his book 'The Birth of the Clinic' (1989b) with the sentence: 'This book is about space, about language, and about death; it is about the act of seeing, the gaze' (Foucault, 1989b, p. ix).

Foucault believed that a hospital 'creates disease by means of the enclosed, pestilential domain that it constitutes, creates further disease in the social space in which it is placed' (Foucault, 1989b, p. 20). Within this social space of a hospital:

Doctor and patient are caught up in an ever-greater proximity, bound together, the doctor by an ever more attentive, more insistent, more penetrating gaze, the patient by all the silent, irreplaceable qualities that, in him (sic), betray-that is, reveal and conceal-the clearly ordered forms of the disease (Foucault, 1989b, pp. 16-17).

The physical space of the hospital allows for the gaze of the doctor to order forms of disease just as the panopticon allowed for prisoners to be subjected to surveillance and knowledge concerning offending behaviour to be formulated. The gaze is more

than observation, it is 'penetrating'; it does not see the person but instead allows for discourse to be formulated and as Foucault writes in 'The History of Sexuality: 1', 'Discourse transmits and produces power: it reinforces it, but also undermines it and exposes it, renders it fragile and makes it possible to thwart it' (Foucault, 1998, p. 101). For Foucault, 'It is in discourse that power and knowledge are joined together' (Foucault, 1998, p. 100).

Power and knowledge operate through discourse. It is discourse which enables people to be 'othered', whether they are the sick, prisoners or the mentally ill. In 'The History of Sexuality: 1' Foucault discusses how sexuality is used as another area where people are controlled, but the motivation was for the affirmation of the Same, rather than the exploitation of the Other. Although the result was exploitation, this was not the primary concern:

The primary concern was not repression of the sex of the classes to be exploited, but rather the body, vigor, longevity, progeniture, and descent of the classes that "ruled". ...it has to be seen as the self-affirmation of one class rather than the enslavement of another: a defence, a protection, a strengthening, and an exaltation that were eventually extended to others-at the cost of different transformations-as a means of social control and political subjugation...What was formed was a political ordering of life, not through an enslavement of others, but through an affirmation of self (Foucault, 1998, p. 123).

The concept of the gaze has a number of applications to this research. Firstly, the diagnosis of people with Asperger's syndrome is given by professionals. This view is gained by a professional understanding of how people with Asperger's syndrome deviate from the 'norm'. It is affirming of neuro-typical as 'typical'. It was in the affirmation of neuro-typical professionals of the 'normality' of being neuro-typical that put people with autism outside of what is considered to be normal. Secondly, this

understanding informed the design of the research as it gave me an awareness of how as a neuro-typical professional I was part of the 'othering' of people with Asperger's syndrome. I had read the literature as a social worker and had been influenced in my approach by the view of autism as a deficit. My aim in this research was to work differently with people with Asperger's syndrome. I wanted to find, together with them, a way to challenge the way power operates with people who are regarded as having a deficit. I wanted to co-create with them a research space in which they are not subjected to a gaze, one in which I learn from them and they from me rather than one in which I operate from the discourse of Asperger's syndrome as deficit.

#### **iv)      Disclosive space**

A further spatial notion that is useful to my research is that of a 'disclosive space'. The naming of this concept was actually an adaptation of Foucault's work made by Dreyfus, based on a Heideggerean interpretation (Dreyfus, 2004). In his lecture 'What is an author?' delivered in 1969 to the Société Française de philosophie, Foucault states:

It is easy to see that in the sphere of discourse one can be the author of much more than a book - one can be the author of a theory, tradition, or discipline in which other books and authors will in their turn find a place. These authors are in a position that I will call "transdiscursive." This is a recurring phenomenon – certainly as old as our civilization... in the course of the nineteenth century, there appeared in Europe another, more uncommon, kind of author, whom one should confuse with neither the "great" literary authors, nor the authors of religious texts, nor the founders of science. In a somewhat arbitrary way we shall call those who belong in this last group "founders of discursivity" (Foucault, 1969, no pagination).

Dreyfus interprets what Foucault says:



What Foucault discovers is a kind of writer who is able to establish a local clearing which one might call a disclosive space. Foucault calls such figures founders of discursivity. This opens a new style of discourse... A founder of discursivity in opening a disclosive space sets up a struggle of interpretations which starts a new line of history (Dreyfus, 2004, no pagination).

A disclosive space allows for the possibility of change. In a society organised by neuro-typical people, a metaphorical space created with people with Asperger's syndrome could be called a disclosive space. A 'local clearing' is a very apt metaphor as in order to create this space, it has to be different from the landscape in which it is situated. This is significant as the co-researchers and I were trying to establish or co-create a 'clearing' or space which was different from the space that surrounded it. The co-researchers and I wanted to step aside from the deficit based understanding of Asperger's syndrome in order to see what people with Asperger's syndrome think. We wanted to understand the experience of people with Asperger's syndrome through the interpretation of the co-researchers rather than through the discourse of professionals. We wanted to start a 'new style of dialogue', a research project in which people with Asperger's syndrome were regarded as experts-one in which *their* experience was regarded as authentic and given credence rather than that of the discourse of professionals.

#### **v) Criticism of Foucault's view of power**

One of the criticisms of Foucault is that his account of power 'necessarily leads to a relativising of ethics which in turn attacks the foundations of democracy and the possibility of freedom either as an ideal or a practice' (Barker, 1998, p. 43). This is an important criticism as a framework based on a theoretical position that does not allow for empowerment would be problematic for my value position as a social work researcher. However, Crampton and Elden (2007) argue that Foucault was not a defeatist. They state that his view was more that liberation and freedom were desirable but that this would not be achieved through legislation. 'Rather, freedom is a

practice or a process that has to be constantly undertaken' (Crampton and Elden, 2007, p. 7). As Foucault states:

I do not think it possible to say that one thing (architectural project) is of the order of 'liberation' and another is of the order of 'oppression'. There are a certain number of things that one can say with some certainty about a concentration camp to the effect that it is not an instrument of liberation, but one should still take into account-and this is not generally acknowledged-that, aside, from torture and execution, which preclude any resistance, no matter how terrifying a given system may be, there always remain the possibilities of resistance, disobedience, and oppositional groupings (Foucault, 1984, p. 245).

For this research, the 'possibilities of resistance' are important. It is these possibilities that would be explored in the creation of a co-created autistic space that is at the heart of this research. A co-created autistic space would be a disclosive space. In my research this would be one in which I as a neuro-typical researcher together with my autistic research partners find a way of working together collaboratively.

#### **vi) Influence of Foucault**

Foucault's work on space has influenced writings in a number of disciplines including philosophy (Doel and Clarke, 2004), feminism, in particular the work of Judith Butler (Hubbard, Kitchen and Valentine, 2004), sociology (Clarke and Doel, 2004), social science (Batterbury and Fernando, 2004) and geography (Philo, 2004). Later writers have been inspired by his concept of space and have applied spatial analysis to a wide variety of subjects (Valentine, 2001) including 'geographies of disability' (Gleeson, 1999). I could not find any application of the concept to autism or Asperger's syndrome in the literature. I will explore some of the applications I did find in the literature and these will provide pointers to how I could use the concept of space in my own research.

I will therefore now examine what autistic writers have said about their concept of space, about neuro-typical space and autistic space.

#### **4. Use of the concept of space by people with autism/Asperger's syndrome**

In the previous chapter, I traced the literature regarding autism and Asperger's syndrome from the original papers of Kanner and Asperger. I noted the language that was used, and in particular the way children with Asperger's syndrome and autism were portrayed as being from a different world and not fitting into 'this world' (Asperger, 1991, p. 66). The language used of people with Asperger's syndrome is much more obviously spatial than the language used of the groups of people that Foucault referred to. Foucault used his historical methods, his genealogies, to show how people were 'othered' and how power operated through discourse. He used the concept of the gaze to show how it is professionals who not only control people, as with the prisoners, but who also construct discourse through which power operates. What Foucault did not discuss was the view of the people themselves who were the subjects of his work. Foucault did not use a polemic style as he thought it did not achieve his objectives (Yates, 2002, p. 40). Quite the reverse, 'he refused to propose a programme of action or to state explicitly what must be resisted because he believed that there are inherent dangers when an intellectual presumes to undertake such a task' (Yates, 2002, p. 40). Foucault writes; 'I'm not convinced that intellectuals – starting from their bookish, academic, and erudite investigations-can point to the essential problems of society in which they live' (Foucault, 1991, p. 151).

For this reason, Foucault did not discuss whether the subjects of his study viewed themselves as different or 'Other'. What is really interesting about the literature written by people with both Asperger's syndrome and autism is that they also portray themselves spatially, as living in a world which is 'alien' to them. This offers validation to the approach of using spatial analysis in the research.

An interesting question is how much the literature, or in Foucault's terms, the discourse of professionals describes Asperger's syndrome or how much it shapes an

understanding of it. Hacking (2009 and 2010) and McGeer (2010) take the view that the literature, including the many works of fiction about or including characters with autism, as well as the media, have had an influence on how people with autism experience their own autism. Hacking writes:

Different kinds of items influence each other in complex ways. Novelists study autobiographies, whose authors learn from theorists. Parents pick up ideas from novels when they are thinking about their children. We all watch movies and documentaries (Hacking, 2009, p. 1467).

McGeer (2010) talks of the 'transformative power' of autistic autobiographies. As a caveat, it is possible that the autistic writers have been influenced by neuro-typical writers. However, the literature written by people with autism or Asperger's syndrome does give their view of their experience, even if it is influenced by a multiplicity of other sources. It demonstrates how they understand their 'autistic space' as well as the space of neuro-typical people and the relationship between the two. However, it also has to be borne in mind that most publications are managed by neuro-typical editors and targeted at a neuro-typical audience. It is therefore possible that what the autistic people write is influenced by those two factors. An autistic space has different meanings in the literature. It can refer to a private world (O'Neill, 1999), an actual physical space (Sinclair, 2010) that is organised to suit an individual with autism or how autistic people experience the world through the way it is organised (Sinclair, 2010). The metaphor of space is used widely in literature in discussing the experience of people with autism. A glance at some of the titles of autobiographical books by people with Asperger's syndrome is indicative of how they view their relationship to the world of neuro-typical people; 'Through the Eyes of Aliens' (O'Neill, 1999), 'Inside Aspergers Looking Out' (Hoopmann, 2013), 'Martian in the Playground' (Sainsbury, 2009) and 'Women from another Planet; Our Lives in the Universe of Autism' (Miller, 2003). 'How to be Yourself in a world that's Different: An Asperger's syndrome Study Guide for Adolescents' (Yoshida, 2007) is written by a neuro-typical writer and echoes the same

idea. It seems that neuro-typical people and autistic writers both use the metaphor of the relationship between two spaces to describe relationships between people with autism and neuro-typical people.

As I have already demonstrated in the previous chapter, through the discourse that professionals produce, they have characterised people with Asperger's syndrome as living in a different world. In Foucault's work, power and knowledge operate through discourse. What the status is of the literature that people with Asperger's syndrome write and whether it is discourse as determined by Foucault is an interesting point. Hacking's point (above) is that the accounts and representations of neuro-typical people could have influenced the writings of people with autism. If this is the case, then their own writings are an extension of the narrative of professionals as they just echo their views. They are the subject of power relations and are merely expressing the dominant view of them as 'Other'. However, there does seem to be some resistance to the dominant views of neuro-typical people in the writings of people with Asperger's syndrome. Many autistic writers also use spatial metaphors and do seem to claim that they have their own world or space. Bogdashina (2006), a neuro-typical writer refers to seeing autism from 'the outside'. I want to look at how those on the 'inside' understand their autistic world and how this relates to that of neuro-typical people.

Lawson (2001), a writer with Asperger's syndrome has the subtitle for one of her books as 'An Insider's View'. She includes the following poetic account:

#### **Autism Is**

Autism is: being present in the world,  
But not entirely of it.  
I am one step removed and curled,  
The switch just doesn't click.  
I perform the role of my perception,

And play many parts so well.  
But minus files for my redemption,  
My part in life cannot tell.  
Life is like a video,  
I watch but cannot partake.  
My uneven skills are but an echo,  
Of the frustrations which I hate!  
However, my focused use of time and space,  
I would not give away.  
I know that I am especially placed,  
For some developed career one day!  
(Lawson, 2001, pp. 12-13).

The picture is painted vividly of an individual, who is not at ease in a world dominated by neuro-typical people, but nevertheless appreciates her own unique qualities and would not 'give them away'. The autistic space is where she feels comfortable. When discussing whether Asperger's syndrome is a 'milder' form of autism, Lawson comments, 'For many of us with this diagnosis, we experience our disability in a neuro-typical world as anything but mild!' (Lawson, 2001, p. 17). Lawson seems to accept the precept that Asperger's syndrome is a 'disability', (in the language of the social model of disability, Lawson is referring to an 'impairment' here), without question but links it to living in a neuro-typical world. It is not so much having Asperger's syndrome that presents her with difficulties, but having to live in a world which is organised by and for neuro-typical people.

Lawson (2006) comments that the triad of impairment presents people with autism as 'damaged, ruined, injured or faulty in these three areas' (Lawson, 2006 p. 68). She believes instead that she and others with autism have a 'different learning style'. Although Lawson does not expand on her expression of being 'present in the world but

not entirely of it', she gives the same overall picture of separation. The fact that people with autism are regarded from a deficit model is what she laments.

Williams (1996) describes her autism:

'Autism' is spoken of by some people as a jigsaw with a missing piece. I experienced my own 'autism' as one bucket with several different jigsaws in it, all jumbled up and all missing a few pieces each but with a few extra pieces that didn't belong to any of these jigsaws (Williams, 1996, p. 1).

Williams was diagnosed as having autism, rather than Asperger's syndrome, but writes in a similar vein to people with Asperger's syndrome in terms of separation from other people. She discusses her over-sensitivity to sensory stimulation at the same time as having difficulty in 'processing meaning' and how this made her feel like an 'alien'.

Williams describes how she:

...grasped the absolute emptiness of what the world held for me. My answer to this was to follow and mimic anybody who would take me along for the ride and to move through life as fast as possible so I didn't have to stop to feel how bad and out of control it all felt (Williams, 1996, p. 3).

In her jigsaw metaphor, Williams is alluding to having a different experience of the world to other people. It had some jigsaw pieces missing, but she had extra jigsaws and extra pieces. Her autistic space was distinctly different to that of neuro-typical people and to try and fit into the world that other people inhabited, she had to mimic people from it.

Willey (1999) entitled her autobiography 'Pretending to be Normal', which echoes the sense of being different and having to mimic as Williams describes. She writes, 'When I was in high school, I was only beginning to see how peculiar my world was-not wrong or embarrassing or unessential-just peculiar and different. I was ok with that, then. I

never minded standing aloof or apart from the crowd. I never felt lonely' (Williams, 1996, p. 44).

The theme of profound difference between neuro-typical people and people with autism can also be found in the literature written by family members. Barnhill (2007) in her book entitled 'At Home in the Land of Oz' wrote that her book was 'the story of how I learned to speak another language, the language of my sister Becky. And how I found my own meaning in our strange conversation...' (Barnhill, 2007, p. 10).

From the literature, it seems that both neuro-typical writers as well as autistic writers see people with Asperger's syndrome and autism as being uncomfortable in the world of neuro-typical people. I could not find any writers with Asperger's syndrome or have met any personally or their family members who took issue with the fact that they are different from other people and all seem to accept that they do find difficulties in the areas that theorists indicate. Although they do not all use metaphors that suggest inhabiting a different space, it is possible to understand what they are saying about their experience in this way.

## **5. What is an 'autistic space'?**

What is disputed by autistic writers is the assertion that their 'autistic space' is inferior to that of neuro-typical people. They sometimes take issue with the language used, which is indicative of this approach as in Lawson above. O'Neill (1999) writes:

It is quite tiring to read book after book denouncing Autism as a horrible condition. I am qualified to offer the opposite opinion. The theme of this book is to say that difference can be wonderful, and Autism shouldn't be tampered with or altered. Autistic people shouldn't be changed. They shouldn't be banished, ridiculed or forced to act as anything other than what they are, naturally (O'Neill, 1999, p. 13).



You can't judge the world of another as inferior, because you don't live in that world. ...An autistic perception is just different from other perceptions....The autistic world is comfortable. It is a safe place to ground oneself in (O'Neill, 1999, p. 21).

O'Neill's assertion that the autistic world is 'comfortable' and a 'safe place' emphasises the difference that autistic people experience between their autistic space and neuro-typical space. O'Neill explains why it is important for autistic people to be able to retreat to what she calls an 'inner world':

The inner world is a way for the individual to feel grounded. It gives private fortitude. It can comfort when the surrounding environment seems to be erupting in chaos. It must be remembered that, just as the person with Autism is handicapped in the outside, big world, the person of the big world is also in many ways handicapped in the autistic world (O'Neill, 1999, p. 21).

O'Neill experiences being 'handicapped' (I use the term 'disabled' in this thesis) in the world of neuro-typical people. She uses the word 'world' in two ways here. Firstly, an 'inner' world where she needs to retreat in order to escape the 'chaos' of the 'big world'. Secondly, she refers to it as a place in which the neuro-typical or 'a person in the big world' is 'handicapped'. This second point cannot refer to her inner world as this would be inaccessible to others. The autistic world or space, as referred to by people with autism, seems to refer to how they experience the world and this is through how the environment is organised. The environment needs to be organised in a way which is 'comfortable' for the autistic person, in a way which is consistent with their sensitivity to stimuli, their need for order and predictability and their need to have control over what they do and experience. An autistic space, in this context, is a metaphorical space where the organisation of the environment or activities is such that the autistic person feels comfortable and able to understand interactions with others. What this space might look like differs from person to person, but there are commonalities as already indicated.

Hoopmann (2013), a writer with Asperger's syndrome writes that people with Asperger's syndrome are people who may have:

- Difficulties relating to others in social situations
- Difficulties understanding nonverbal communication
- Heightened sensitivity to touch, sight, hearing, taste and smell
- Set routines and a strong preference for order
- An intense ability to focus in specific interest areas
- Great loyalty towards others
- A unique mind which is able to see life from a new perspective (Hoopmann, 2013, p. 2).

The first three of these characteristics are what the autistic person experiences in the neuro-typical world, although the third is also experienced in an autistic world. The next two describe elements of the autistic world. When either a literal or a metaphorical 'space' is ordered in a way that suits the autistic individual and allows for concentration on special interests, the autistic person is more easily able to show the qualities referred to in the last two. These last two are much more difficult to achieve if a space is not ordered and organised in a way which is 'comfortable' to the autistic individual. The qualities that an autistic person may have, of preference for order and an intense ability to focus on an area of special interest are excellent qualities for participating in research. If the research space that we sought to co-create could ameliorate the experience of the co-researchers as identified in the first three characteristics then the last two characteristics could be realised and be of huge benefit to the research.

One article, describes very graphically what it is like to be an autistic person living in 'Neuro-typical space' or a world which is organised by and for neuro-typical people. Sinclair, an autistic adult identifies three kinds of spaces, Neuro-typical space, One's own space and a Shared autistic space (Sinclair, 2010). He describes the experience of an autistic person living in a neuro-typical space:

Being autistic among neurotypical people is likely to consist of not understanding what other people are doing, or why they're doing it, or what they expect us to do; not being understood when we ask questions or try to join in, being misunderstood and misinterpreted in hurtful ways... being subjected to noxious stimuli as the price of social participation; and being expected to maintain a level and pace of participation that is overwhelming and draining for us (Sinclair, 2010).

By 'One's own space', Sinclair means a physical space in which an autistic person can have control over their environment. 'Having one's own space means having control over the space itself, over what one does in the space, and over who has access to that space' (Sinclair, 2010).

This is obviously referring to a physical environment which has been organised to suit the person with autism. Interestingly, Sinclair does identify difficulties with 'One's own space':

But with that increased freedom in one's own space comes decreasing external structure. Many autistic people have considerable difficulty managing routine self-care and maintenance functions without someone to remind and assist us. We can easily find our own spaces and our lives devolving into chaos if we live completely on our own, with no one else coming into our space (Sinclair, 2010).

The characterising feature of 'One's own space' is that it is organised by the autistic person. This element of control is what makes it a space belonging to an autistic individual. For Sinclair, any environment created by people who are neuro-typical is not an autistic space, whether it be 'good or bad'. The fact the neuro-typical people are 'in charge' and make the rules means that it cannot be an autistic space. 'The very fact that NTs (neuro-typicals) are creating and managing a program or a service, for the benefit of autistic participants, conveys the perception that autistic people are helpless and dependent on NTs to take care of us' (Sinclair, 2010). As in 'One own space, in a

shared autistic space, autistic people are in charge. 'Autistic people determine what our needs are, and autistic people make the decisions about how to go about getting our needs met' (Sinclair, 2010).

(A similar debate is discussed in Chapter Four regarding research and who controls the research. I will not discuss control of 'spaces' here as there is a lengthy discussion in that chapter).

Autreat is a conference held in the UK *by and for* autistic people. It is 'centred around autistic people's needs, interests and sensitivities' (Autoscape, 2012) and is an example of a shared autistic space. The organisers, who are themselves autistic, assist people with autism to feel comfortable by organising the conference in such a way that it is helpful to autistic people. A badge system has been devised with those wearing a red badge indicating that they do not want to interact with other people, those wearing a yellow badge indicating that they do not want to be interacted with unless they indicate this, those with green badges indicating that they would like to socialise, but find it difficult, so would like others to initiate interactions and those with a white badge indicating that they are 'able to regulate' their own interactions. Conference attendees can choose to wear tinted glasses or earplugs to reduce the amount of stimulation where necessary. 'Autistic behaviours' including 'stimming' (repetitive movements), echolalia (repeating speech), avoidance of eye contact and other behaviours are all 'normal'. A designated quiet room is set aside for attendees to go when 'things are getting too much' (Autoscape, 2012). This provides a very good model for what a shared autistic space might look like and highlights these considerations for my research.

Talking of the experience of being in the 'own space' belonging to another person with autism, Sinclair was 'feeling that, after a life spent among aliens, I had met someone who came from the same planet as me.' Speaking of the experience of people with autism meeting each other in an autistic space such as a retreat or conference, he

states that the 'same planet' metaphor, as well as metaphors about 'speaking the same language' or 'belonging to the same tribe,' are often used by people with autism. He states, 'One participant at the first Autreat in 1996 summed it up saying, "I feel as if I'm home, among my own people, for the first time. I never knew what this was until now"' (Sinclair, 2010).

What is interesting about Sinclair's paper is that it demonstrates how people with autism seem to be claiming that they belong to a different space. They do have different ways of living in the world from neuro-typical people and it is suggested that only when they can organise a space of their own that they really feel 'at home' (Sinclair, 2010). This is quite different from Foucault's concept of 'Othering', as it is the people with autism themselves who are saying that they are 'Same' and that neuro-typical people are 'Other' from them. Sinclair describes the experience of neuro-typical people who attended one of the retreats for people with autism (which he calls a 'shared autistic space'). He comments on their feelings of discomfort and states that this would be useful for people to recall as this is similar to what people with autism feel in neuro-typical space. I had not read of the autreats when I started my research so did not have the benefit of this model to inform how we co-created our research space. It is an excellent example of what we were aiming to achieve i.e. a research space in which we found ways for all members of the research to work in ways that were comfortable to them.

The literature also demonstrates that different individuals with autism might need different characteristics for their own autistic spaces (Grandin, 2006). This is an indication of the fact that 'one's own space' would be different between individuals with autism. It also indicates the difficulties which would be involved in creating a shared autistic space as one person's needs could be opposite to another's, rather than just different. Grandin (2006) prefers to 'think in pictures' as this is how she makes sense of the world. She is able to use visualisation to understand what others are thinking but states that not all people with autism think this way. She comments

on Williams who prefers telephone conversations rather than face to face conversations with people because she found that this resulted in less stimulation for her to process. Grandin states that other people with autism have also reported that the phone is a better means of communicating than face to face. This is because some people find it difficult to process the visual stimulation of seeing someone along with the auditory stimulation of listening to someone. Other people with autism do not find this to be true for them. Grandin states that set routines, times, particular routes and rituals all help to get order into lives which otherwise seem unbearably chaotic to the person with autism. This is an indication of how different an autistic space might be from a neuro-typical space but also how each person's autistic space might be different from that of others- a fact that is conceded by Sinclair (2010).

On a day to day basis, most people with autism do not have the opportunity of living in an autistic space. The collision of the autistic and neuro-typical worlds finds expression in a factual account of a man with Asperger's syndrome and his neuro-typical wife. Slater-Walker and Slater-Walker (2002) write of what they call their 'Asperger marriage'. Attwood (2002), in his forward writes,

Unfortunately the achievement of an intimate relationship is at some personal cost both to the person with Asperger's in terms of the mental effort required to maintain the relationship and to their partner in having to change their expectations of a relationship (Attwood, 2002, p. 9).

The book details the difficulties that each partner experienced and the mutual understanding that they come to. The fact that they wrote a book about this with the hope that it would help others, perhaps demonstrates the extent of the difficulties that were encountered by both partners in bringing the neuro-typical and autistic worlds together.

Grandin's writing showed me again the importance of trying to make the experience of the co-researchers that of being in an autistic space. I noted Sinclair's statement that a neuro-typical person cannot create an autistic space. It strengthened my resolve to co-create a shared autistic space together with the adults with Asperger's syndrome that would form the research group. Slater-Walker and Slater-Walker made me even more aware of the importance of this task to have a successful participatory research project but also showed the possibility of neuro-typical people and people with Asperger's syndrome achieving this together.

The National Autistic Society (2009) outlines an approach to adapting the environment for people with autism called 'SPELL'. This stands for 'Structure, Positive, Empathy, Low arousal and Links' (The National Autistic Society, 2009, p. 4). It explains the need for structure and predictability, providing a positive approach, trying to understand the person with autism, providing a calm environment and providing good communication between family members and professionals. Although this is aimed at parents of children with autism, this does indicate what is important in an autistic space. It is the lack of predictability and structure, high arousal and the lack of positive regard for people with autism that seem to make the neuro-typical space an 'alien' environment for people with autism.

#### **6. People with autism and Asperger's syndrome living in a neuro-typical space**

Muggleton (2012) in his autobiographical book with the telling title 'Raising Martians: From Crash- Landing to Leaving Home' uses the triad of impairment to explain autism and Asperger's syndrome. He uses 'we' when he discusses the three areas of impairment, an indication of his acceptance of these for himself and others on the autistic spectrum. He states, 'What we all have in common is a deficit in social understanding. Essentially this means we are not 'reading' other people' (Muggleton, 2012, p. 36).

Muggleton (2012) cites a lecture that Attwood gave when he said that the main difference between autism and Asperger's syndrome is what he calls 'happiness'. Muggleton explains that this means that people with autism are different from the general population, but are unaware of this, whereas people with Asperger's syndrome are also different but are aware. They feel the need to conform, but are unable to. According to Muggleton, people who are autistic are 'happy' because they are unaware that they are different, whereas people with Asperger's syndrome are 'unhappy' because they are aware that they are different. People with Asperger's syndrome inhabit their autistic space but feel that they should be able to live and function in the neuro-typical space. I think this is an unhelpful way of thinking about the difference as it reinforces the view that autism is deviant from the 'norm'. It is reminiscent of the distinction cited above by Van Krevelen of autistic children living in a different world and children with Asperger's syndrome being in the world but unable to relate to it. Muggleton comments that the culture of society has made people think that different is 'abnormal or subnormal', whereas in fact, it is just different. The difference between the way that neuro-typical people and people with autism behave is captured by Bogdashima (2006) who cites a dryly humorous definition of 'neuro-typical syndrome' by Muskie, an adult with Asperger's syndrome:

Neurotypical syndrome is a neurobiological disorder characterized by preoccupations with social concerns, delusions of superiority, and obsession with conformity. Neurotypical individuals often assume that their experience of the world is either the only one, or the only correct one. NTs are often intolerant of seemingly minor differences in others. When in groups NTs are socially and behaviourally rigid, and frequently insist upon the performance of dysfunctional, destructive, and even impossible rituals as a way of maintaining group identity. NTs find it difficult to communicate directly, and have a much higher incidence of lying as compared to persons on the autistic spectrum. NT is believed to be genetic in origin (Bogdashina, 2006, p. 88).



This captures very well the challenges of people with autism living with the complexities and nuances of the neuro-typical world. It challenges the taken for granted assumptions which were explored in Chapter One of a deficit being attributed to people with autism.

Other writers have turned the spatial metaphor around and asserted that people with autism are from the same world as neuro-typical people. In the forward to Miller's book, 'Women from another Planet; Our Lives in the Universe of Autism', Singer (2003) writes:

This seems like a good place to come clean. What it all boils down to is this. We are *not* from another planet. We tricked you. We made you look. We are from right here, Planet Earth. We are an integral part of this earth's ecosystems, its intricately inter-dependant network of niches and potentialities. What we are is the first of a new wave of consciousness in a planet coming to awareness of its extraordinary diversity...We are part of a groundswell of what I want to call *Neurological Liberation* (Singer, 2003, p. xii).

Singer and Muskie want to be seen as coming from the same world as neuro-typical people. For Muskie, there is arrogance in the assumption that the differences of autism are inferior-that the autistic space is not as valid as the neuro-typical one. For Singer, the two spaces are part of what makes up the world, part of its 'extraordinary diversity.'

This can be applied to the discourse on Asperger's syndrome (as discussed in the previous chapter). People with Asperger's syndrome are regarded as 'Other' through a medicalisation of their differences as impairments and one way that this is demonstrated is through the 'triad of impairment' (Wing, 1996). This marks them out as fundamentally different from other people but in a way which is portrayed as deficit. Using Foucault's analysis of power operating through discourse and creating a

space in which some sections of society are regarded as 'Other' it is possible to see how the characterisation of Asperger's syndrome as cognitive deficit has created a space for them which is separate from that of neuro-typical people.

What the literature has shown is that autistic writers make generous use of spatial metaphors to explain their experience as well as to explain how their space is different from that of neuro-typical people. They are clear about what they need in order to be 'comfortable' in a space. I now want to explore how the literature provides an enhanced understanding of space. I will outline how it can form a framework to explore further the experience of people with Asperger's syndrome. I will also demonstrate how it will help me conduct research that is enabling to a group of adults with Asperger's syndrome, or to put it another way, what I needed to consider together with the group so we could co-create an autistic space which would enable the co-production of our research.

## **7. Space as a concept to frame the research method**

As I have discussed above, Foucault used physical spaces to demonstrate how society had segregated and monitored some sections of society. Later writers build on this insight and suggest ways of understanding space. Massey (2005) suggests that the use of space can provide the following propositions:

1. That it can be understood 'as the product of interrelations; as constituted through interactions, from the immensity of the global to the infinitely tiny.'
2. 'That we understand space as the sphere of the possibility of the existence of multiplicity in the sense of contemporaneous plurality; as the sphere in which distinct transjectories coexist; as the sphere therefore of coexisting heterogeneity. Without space, no multiplicity, without multiplicity, no space.'
3. 'That we recognise space as always under construction. Precisely because space on this reading is a product of relations-between, relations which are necessarily embedded material practices which have to be carried out, it is

always in the process of being made. It is never finished; never closed' (Massey, 2005, p. 8).

These propositions demonstrate perfectly the use of spatial analysis in the literature as well as the application I wish to use in my own research (which I will discuss later in this chapter).

One of the applications of a spatial analysis has been in relation to the lives of children and young people. Holloway and Valentine (2000) in writings of 'children's geographies', state that '...geographical studies can add texture and detail to the currently rather broad-brush analysis of the social construction of childhood' (Holloway and Valentine, 2000, p. 9).

These geographical studies use physical 'everyday' spaces such as the home, school and the city to demonstrate how children's identities are constructed through the control and regulation they are subjected to in these 'spaces'. Thus the concept of space moves beyond the physical space to what children experience by way of being regulated by adults. Spaces such as schools are 'institutional spaces' which serve society by socialising children into their role and place within society (Holloway and Valentine, 2000, p. 14). What is implicit here is that power operates through the way that spaces are organised. Institutional spaces allow for the regulation of children in such a way that they learn that their place is subservient to adults, their role is to obey what adults say. This echoes Massey's first proposition about space, that it is 'the product of interrelations' (Massey, 2005, p. 8).

Seeing spaces as vehicles of social control has been turned round by some writers who saw possibilities of spaces being controlled by groups that are subject to control in other spaces. Moss and Petrie (2002) talk about an adventure playground which is used by children, many of whom have not been succeeding at school, as the 'children's

own space' (Moss and Petrie, 2002, p.1). The playground is important to them because it is a refuge for them where they can be themselves and:

They use it for their purposes and their friendship groups....In the course of using the playground, children gradually come to take responsibility for it. They rake the sand, make a cup of tea, take over from staff in games with younger children and get involved in the staff group activities in other ways. The manager says it would be impossible to operate with so few staff without the children's consent: "staff respect children for what they are, not for what they want them to become. This is a refuge where they can be themselves" (Moss and Petrie, 2002, p. 1).

Moss and Petrie (2002) use the image of what happened in the physical space of the playground to reconceptualise provision for children. The authors challenge the conceptualisation of what children are, what constitutes a 'good childhood' as well as the purposes of public provision for children. They state that their book is about:

...the possibility of public provisions for children being envisioned as spaces for children and for the childhoods children are living here and now, as well as for creating relationships and solidarities between children, between adults and between adults and children (Moss and Petrie, 2002, p. 2).

Moss and Petrie use the application of what can happen in a space which is 'owned' by children to challenge the way that services are 'justified', such as the 'the rescue and protection of children who are needy, weak and poor' (Moss and Petrie, 2002, p. 2). They use the concept of space to question constructions of childhood and the hierarchical relationships between children and adults. Implicit in their work is the idea that power can be distributed in a different way in service provision. Power operates through the way that childhood is constructed and this echoes Holloway and Valentine's view that children are socialised into their roles in society. For Moss and

Petrie, there is the possibility of learning from the children's own space and applying this to service provision.

From an understanding of space as demonstrating socialisation into subordinate positions in society (Holloway and Valentine, 2000), to seeing it as providing examples of what can be achieved (Moss and Petrie, 2002), writers have used it as a concept to show how power is either monopolised or distributed. Hickey and Mohan (2004), when discussing citizen participation in the 'Third' World identify the concept of space as allowing for understanding participation in terms of it being 'situated' and represents 'the bounded yet permeable arenas in which participation is invited, and the domains from within which new intermediary institutions and new opportunities for citizen involvement have been fashioned' (Hickey and Mohan, 2004, p. 75). This has moved away from what takes place in a physical space to what occurs in 'arenas'. It is concerned with the relationships between groups of people and how much participation is actually invited. 'Bounded yet permeable' indicates the uncertain nature of this type of space. It is changeable as it is about invitation. The power is with those who do the inviting. This makes participation different from the institutional space of Holloway and Valentine (2000) and different from the children's own space of Moss and Petrie. Instead, the concept of space is used to map how much participation takes place.

Cornwall (2004) shows how the concept enables an analysis of 'participation sites' in terms of how it 'comes to be populated' to issues of 'discursive closure' or how issues are shaped, to how sites are 'animated' or 'domesticated', to what opportunities are absent as well as how political agency gives rise to a new voice. For Cornwall, it is the analysis of 'the dynamics of power, voice and agency' which can help understand what happens in a participative space so they can be further developed to be more effective sites of participation. This echoes Massey's third proposition about space, that it is 'always under construction' (Massey, 2005, p 8).

Other writers have contributed to the concept itself and expanded its theoretical basis. According to Urry (1995), Simmel is the most important classical contributor to the idea of space. Drawing on Simmel's paper, 'the Metropolis and Mental Life' (2000), originally written in 1903, Urry identified five qualities of spatial form that are found in social interactions which transform an empty space into 'something meaningful'.

These qualities are:

- the exclusive or unique character of a space;
- the ways in which a space may be divided into pieces and activities 'spatially framed';
- the degree to which social interactions may be localised in space;
- the degree of proximity/distance especially in the city and
- the role of the sense of sight; and the possibility of changing locations and the consequences especially of the arrival of the 'stranger' (Urry, 1995, p. 8).

Although Simmel is referring to physical spaces the above begins to show how using the concept of space could be used to explore the use of power and social relationships in individual spaces. Simmel's qualities of a space capture the propositions from Massey (2005) as they are concerned with the interrelations of her first proposition. I wanted to find a framework of analysis based on spatial understanding and so I reframed Simmel's qualities of actual physical spaces as questions to reflect on metaphorical spaces<sup>1</sup>:

- What is exclusive or unique about a space?
- How is a space further divided and by whom?
- How are social interactions in a space different or the same as those in other spaces?
- How does a space relate to other spaces?
- How possible is it for people to inhabit other spaces?

The analysis of space is further explored by Lefebvre, who is cited by Urry as arguing that space is not a 'neutral or a passive geometry' (Urry, 1995, p. 25). It is produced

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<sup>1</sup> In this thesis a 'metaphorical space' is a social rather than a physical space. It is the framing of social interactions in spatial terms which brings fresh insights to practice.

and reproduced and as such represents the site of struggle. For Lefebvre, three elements of physical space should be analysed:

- Firstly spatial practices,
- Secondly, representations of space and
- Lastly spaces of representation, or the collective experiences of space (Urry, 1995, p. 25).

Spatial practices include the action of individuals and planning authorities in how the space is built on and landscaped. Representations of space are 'the forms of knowledge and practices which organise and represent space particularly through the techniques of planning and the state'. Spaces of representation are how space is experienced.

I framed further questions for analysis of a metaphorical space based on Lefebvre's insights:

- What happens in a space? Who sets the agenda for what happens?
- How is this achieved?
- What knowledge is being utilised in a space?
- How do those in a space experience it?

I combined and re-ordered the two sets of questions to explore firstly the space itself and what forms it, and secondly what happens in it, including the experiences of those who inhabit it and thirdly its relationship to other spaces. I decided to omit Simmel's last 'quality of a space' (How possible is it for people to inhabit other spaces?) as I wanted to focus on what happens in a particular space rather than explore broader relationships between spaces. I added a last question in acknowledgement of Massey's third proposition about space being under construction as this was the only one of the three propositions that did not seem to be covered in the questions:

- What is exclusive or unique about a space?
- How is a space further divided and by whom?
- What knowledge is being utilised in a space?

- What happens in a space? Who sets the agenda for what happens? How is this achieved?
- How do those in a space experience it?
- How are social interactions in a space different or the same as those in other spaces?
- How does a space relate to other spaces?
- How does a space change? Who is responsible for the change? How is change achieved?

Implicit in these questions is how power is used and by whom. It also recognises the link between power and knowledge. I used these questions to plan my research, to ensure that I was co-creating an enabling space, an autistic space. I also wanted to use this framework to evaluate my research. For ease of reference, I will refer to this set of questions in future as a 'spatial analysis framework'. This would be in the form of an autistic space in the context of this research. Finally, a spatial analysis was developed based on the literature to form and to analyse this research. This spatial analysis is designed to explore how power operates in a metaphorical space and explore the experiences of those in the space. It is designed to address some of the issues in relation to participatory research which will be discussed in Chapter Four. The next chapter will discuss the social model of disability and use the concept of space to discuss how disabled people have been 'Othered' by society. It will further the application of the literature to this research and show how it informed the research method.



## **Chapter Three**

### **Literature Review III: Social Model of Disability**

#### **Introduction**

In the first chapter I traced some of the history of Asperger's syndrome and how it has been viewed through the spatial metaphors of neuro-typical writers. In the second chapter I discussed the concept of space and examined autistic writers' perspectives of their 'world' and how they relate to the neuro-typical world, again through spatial metaphors. Through the first two chapters, I have outlined how my understanding of people with Asperger's syndrome was developed in the context of them being 'Other', of being from a different metaphorical space. I traced how autistic writers also think of themselves as being from a different space or world. I learnt from this the importance of the creation of a 'research space' which is also an 'autistic space' and the implication of this for me as a neuro-typical researcher. I now widen out the discussion of the literature to explore debates around the social model of disability and the context in which it was advocated. These are important debates for this research as it was this model that was the motivation for the research and provided the underpinning view of disability held by the group. I aimed to co-create an *enabling* space with the group of adults with Asperger's syndrome who were to be co-researchers. I will explore the debates in the literature in relation to the social model and determine what an enabling space is in the light of these debates.

#### **1. The social model of disability and spaces that disabled people occupy**

In this chapter I will show that the literature documents historical examples where disabled people were removed to physically different spaces away from non-disabled people. I will also trace how the disabled people's movement strove for the inclusion of disabled people back into society to occupy the same physical spaces as non-disabled people. The literature shows how, in order to do this, disabled people had to organise themselves. They then had to resist the influence of non-disabled people to conform and to be seen as 'tragic' in line with the 'medical model' of disability. The

social model of disability was developed as a result of the struggles of the disabled people's movement. The most recent literature written by disabled academics mourns the decline of the disabled people's movement as some think that big organisations *for* disabled people have taken over the role of representing disabled people. The history of the disability movement will be discussed spatially as disabled people were removed to literally separate physical spaces. The metaphor of space will be used to illustrate the evolution of how disability is perceived by society as well as by disabled people themselves. The concept of a disclosive space, discussed in Chapter Two is applicable here. The new way of thinking about disability which resulted in the formation of the social model of disability can be seen as a 'local clearing' (Dreyfus, 2004) as discussed in the previous chapter. I will also discuss the relevance to this research project of the debates regarding the social model in the literature and its suitability for the research as an underpinning way of understanding disability.

## **2. Historical context-why were people removed to different physical spaces and what were they like?**

The Industrial Revolution saw the beginning of some sections of society, including disabled people being sent away to 'colonies' or 'homes for the mentally deficient' (Atkinson and Williams, 1990, p. 248). Prior to this people with learning and other impairments were generally accepted as part of society and in medieval times impairments were commonplace and accepted (Allday, 2009). Gleeson makes the point that impairment was common and as such accepted by medieval peasants. He states that as a result, 'disability occupied a social space distinct yet embedded within the general terrain of everyday life' (quoted in Allday, 2009, p. 33). The spatial metaphor is adopted to emphasise inclusion which at the same time acknowledges difference or 'distinctness'. Society's attitude towards disabled people changed dramatically with the rise of the Industrial Revolution as the nature of labour changed and people who had previously been able to take part in agricultural work were no longer able to keep up with the pace of more industrial tasks (Allday, 2009). Social relationships changed with the change from collective 'agrarian labour' to individual

‘wage labour’ which meant that those who could not physically keep up with the pace of factory work became dependent on their families and this put families under pressure (Oliver and Barnes, 2012).

With these changes came a lack of tolerance of disabled people being included in society. Allday cites Barnes as tracing the ‘gestation of the disability category’ (Allday, 2008, p. 34) to the nineteenth century when this was accompanied by the medicalisation and industrialisation of the body. What was originally a labour market issue became individualised medical problems (Oliver and Barnes, 2012). People with impairments began to be systematically excluded from society due to these factors and the influence of social Darwinism and the eugenics movement. Disabled people were seen as a threat because of ‘racial’ degeneration (Allday 2008, p. 34). As a result many people were sterilised and sent to colonies, which were often single sex. The *Mental Deficiency Act 1913* required doctors to identify people who were ‘mentally defective’. This identification would either lead to supervision in the community or removal from their families and being sent to live in one of the many colonies. Grace, a woman with a learning disability, was interviewed for ‘Know Me As I Am’, a collection of prose, poetry and art by people with a learning disability, about her incarceration in a colony in 1933 when she was 17. She states, ‘My grandfather didn’t say where I was going. He told me I was going somewhere but he didn’t say where. That’s what got me, he didn’t say where. If he’d said where I were going, I expect I didn’t want to come!’ (quoted in Atkinson and Williams (eds), 1990, p. 157).

Grace stayed at the colony until the 1970s when she moved into independent living. These physical spaces that disabled people were removed to were then regimented in a way designed to control them. Atkinson and Williams (1990) interviewed many disabled people who lived in the colonies and they talk of regimented bath times, institutional routines, gender segregation and physical punishments if people did not follow the strict rules.

Punishment is often detailed in the literature and sometimes this took the form of further segregation. Micheline Mason, a disabled woman experienced physical separation from her non-disabled peers when she attended a 'special' boarding school in the late 1950s. After trying to fight what she saw as the oppressive attitude of staff at the school, she was 'split up' from her 'comrades'. She states:

Our self esteem was so battered that most of us longed to be assimilated into the able-bodied world, believing this to be some kind of passport to eternal happiness. There is nothing like denying access to something to guarantee that you become obsessed with it. (quoted in Campbell and Oliver, 1996, p. 32)

The diary of Thomas (Ryan and Thomas, 1994) details his work as a nursing assistant in a 'subnormality' hospital for adults with a learning disability in the 1970s. He details the degrading treatment and conditions of the hundred adults that lived there at the hands of the staff. One sentence seems to sum up the situation of learning disabled people who have been placed, without their consent in a space away from society: 'From inside the ward you can see the green and the trees through the thick windows, access to them only with a key. Only the staff had keys' (Ryan and Thomas, 1994, p. 31).

Jackson (2000) in his book entitled 'the borderlands of imbecility' traces how the institutions in Victorian and Edwardian England operated as sites where normality and deficiency were defined. The spatial separation of disabled people served on the one hand to rid society of the genetic 'contamination' and on the other to reinforce the difference between 'normal' and 'deficient'. The physical separation was a clear message to disabled people and non-disabled people alike that disabled people were separate from society. The physical segregation then leads to a normalisation of disabled people as being 'other' in society. They did not even inhabit the same physical spaces.

Foucault (1988) discussed how society used to segregate lepers and, when leprosy had largely disappeared, it turned its attention to people with mental health needs with the rise of asylums. I have detailed that the literature shows how society also extended this to disabled people. One example of where the use of a physical space changed to reflect this is Magdalene Hospital in Bath. This was originally built as a Leper Hospital in around 1095. By the 1600s, it was used as a hospital for 'innocents' or 'idiots'. Although it fell into disrepair, the money that was used to fund it was transferred to the 'Bath Idiot and Imbecile Institution' (Carpenter, 2012). Beresford and Branfield (2012) write about how the disabled people were judged to be 'abnormal' and 'defective' at the time of mass segregation to asylums in England. They reflect that disabled people were also separated from each other so the 'insane', the 'deaf' and the 'mad', the learning disabled and the physically disabled all had their own spaces to which they were removed. They state: 'The segregation, isolation and degradation-unintentional or otherwise-of disabled people and service users, were routinised and became the norm...it ...paved the way for how disability is still significantly understood and perceived today' (Beresford and Branfield, 2012, p. 37). Society has used literal physical spaces as well as financial resources to exclude those members of society who are seen as unproductive and a threat to 'normal' citizens and as Beresford (and Branfield point out above, this has framed how disability is viewed today). Many writers in the field of Disability Studies have traced the effects of industrialisation on people with impairments and how this has shaped the way they are seen today. Barnes (2012, p. 13) writes how the forces of 'Industrialisation, urbanisation, changing work patterns and accompanying ideologies: liberal utilitarianism, medicalization, eugenics and social Darwinism-all contributed and compounded ancient fears and prejudices.' He concludes that these forces provided intellectual justification for the removal of disabled people from mainstream society. It is interesting that Barnes writes of the changes for disabled people that are attributed to industrialisation as being rooted in prior prejudices.

For some writers, the processes of industrialisation have led to the concept of dependency. Oliver (1989, p. 9) discusses sociological reductionism and writes of how

'pathological groups' are created by focusing on what different groups have in common; in the case of disabled people, this being dependency. For Oliver, work in an industrial society not only produces goods, but creates 'particular forms of social relations' and an 'industrial proletariat' together with the erosion of communities. He writes of the disappearance of 'previously acceptable social roles' such as beggars and 'village idiots'. The workhouses and asylums performed an ideological function, in that they were 'visible monuments' to those who conformed to the new work system (Oliver, 1989, p. 10). Oliver (1989, p. 11) explains how the perception of dependency created by the process of exclusion means that disabled people are perceived in terms of their dependency and so will be further excluded from employment, thus further creating dependency. Thomas (2007 p. 61) reflects on another implication of the exclusion of disabled people from mainstream society. Rural communities and towns developed without the inclusion of disabled people and so only them 'in view', thus developing in a way that did not consider including them.

Putting into question the notion that all disabled people were sent away to institutions, Roulstone (2012, p. 219) documents examples of where some disabled people were able to continue to work in 'inadvertent shelters' in the form of small-scale workshops or artisan work. A risk of overlooking the craft working, which were not subsumed by the growing factories. Roulstone (2012, p. 219) writes that there are forms of economic activity which did allow some disabled people to continue to work when others were sent to institutions. Roulstone explains that there are parallels to the experience of disabled people in former state socialist countries to those in England. A country structured along communist lines also resulted in disablism in work and Roulstone writes that this may likely be due to a 'broader set of values that structure the complex organisation of labour in "advanced" industrial societies of various forms'.

### **3. What did segregation mean for disabled people?**

One impact of segregation was the negative view it gave disabled people about themselves. The literature details many examples of disabled people's awareness that their past experiences of segregation had an impact on how they regarded themselves. Ann MacFarlane is disabled woman whose interview is quoted in Campbell and Oliver (1996):

I think disability was very much illness-based for me. I was ill. I was perceived to be ill by everybody including the professional people and other people that visited me. I think I perceived myself as being ill, though in retrospect I certainly wasn't most of the time. I was ill at times but I wouldn't have said that was the predominant feature. The predominant feature throughout my institutional life was the fact that I was left in bed a lot of the time when I could have been up. Because I couldn't dress and wash myself, the staff did for me what they felt was adequate and sometimes it was totally inadequate. I was very much kept where they wanted me to be kept (Campbell and Oliver, 1996, pp. 36-37).

Disability conceptualised as illness, as seen in relation to autism, meant that it was perceived as the remit of the health professions to 'treat' it and this often meant that people lived in hospitals. Mason, a disabled man cited in Campbell and Oliver (1996) thinks that the medicalisation of disability has its origins in the National Health Service and he cites the example of the change of culture of where he lived as somewhere that disabled people could 'make a life for themselves' to a place that was run like a nursing home when the National Health Service imposed nursing criteria on it (Campbell and Oliver, 1996, p. 37). The disabled people that contributed to Campbell and Oliver's book describe their dissatisfaction in terms of their segregation from society, their placement in other physical spaces, the way they were treated in these spaces and the inferiority of these spaces when compared to those inhabited by the professionals that worked with them.

#### **4. The disability movement and the struggle over space**

The historical context of categorisation and exclusion sets the context and impetus for the rise of the disability movement. The history of the disability movement also demonstrates the struggles that disabled people have had in order to obtain the same rights as non-disabled people. The movement was actually based on such 'struggles' according to Mason, whose interview is quoted in Campbell and Oliver (1996, p. 18). These were essentially struggles over spaces, which cannot be divorced from issues of power. Non-disabled people controlled the physical spaces, who were sent to them and who were the gatekeepers. Disabled people wanted to be included in society in the way that others were. They didn't want to be physically separated and controlled. They wanted the same rights that non-disabled people enjoyed. Disabled people had been placed in what Freund (2001, p. 697) refers to as a 'disabling space', both physically and in terms of it being a 'disabling space of values'. He uses this term to refer to a physical space which could be physically accessible to disabled people, but which is in fact experienced as oppressive, because of its 'meaning'. Applied here, disabled people had been placed in a space which was physically removed but which also conveyed the meaning that disabled people were inferior and less than human. The disability movement, according to Hughes and Paterson cited in Freund, managed, to some degree, to have 'politicised social and physical space' by calling attention to the exclusion of disabled people from such 'spaces' as the workplace (Freund, 2001, p. 698). The growing awareness amongst disabled people that their lack of capability was linked to how the space was organised in which they lived, made it possible that 'Inhospitable spaces can become focal points of resistance' (Freund, 2001, p. 710).

Mason states that although historically the early struggles for equal rights may not have been called a 'disability movement'; there have always been people who are oppressed who want to be more autonomous and more in control of their lives (Campbell and Oliver, 1996). In the 1970s, disabled people started to reject the idea that an inevitable consequence of their disability was that they could not live in mainstream society (Roulstone and Prideaux, 2012). The 1980s saw a shift in the



understanding of disability with the introduction of the United Nations Declaration of the Rights of Disabled Persons (1975) which contained the statement that organisations of disabled people 'may be usefully consulted in all matters regarding the rights of disabled persons,' (S. 3447.12). From this time a number of organisations arose for disabled people, many of them run by disabled people (Campbell and Oliver, 1996). Some of the literature contains an interesting shift in the use of spatial metaphors. The terms 'insider' and 'outsiders' are used by Campbell and Oliver, (1996, p. 24), two disabled writers, but in relation to the disability movement rather than society. What seems to have taken place is the transformation of a social and political space from being where people are excluded by society to a space where disabled people are able to form a common identity. For the first time, disabled people's own experience began to influence notions of disability (Roulstone and Prideaux, 2012, p. 45). The space had become a place of resistance by disabled people against the 'tragedy' and medicalised view of disability.

## **5. A space of their own**

The disability movement grew from the recognition of disabled people that they would not get the support that they felt that they needed from charities, voluntary organisations or mainstream party politics (Campbell and Oliver, 1996). It was essentially a movement which grew up around the view of disabled people that they were segregated from society, that this was caused by society itself and that disabled people had an equal right to be a part of society along with non-disabled people. Mason states, 'the disability movement is the struggle against oppression, against segregation' (quoted in Campbell and Oliver, 1996, p. 110). Maggie Davis, a disabled woman summarises the view of the disability movement; 'they're shutting me right out just because I'm disabled' (quoted in Campbell and Oliver, 1996, p. 106).

Many disabled people did feel excluded and there remained with some the view that society was really for non-disabled people and it was a space that really belonged to non-disabled people alone. Philip Mason states, 'We really felt that actually it was very

nice of society to let us in' (quoted in Campbell and Oliver, 1996, p. 107). Again, space and power are both implicit in this quotation. 'Society' held the power and could dictate whether or not disabled people were allowed to enter into their literal physical spaces.

Campbell and Oliver (1996) discuss 'transforming consciousness' and state that it was a 'slow and painful process to transform your own view of the world and your place within it' (Campbell and Oliver, 1996, p. 107). Such was the power of the effect of segregation that even disabled people who were involved in the disability movement struggled to see the world as anything other than consisting of one space for non-disabled people and another for disabled people. The transformation from a disabling space to a more 'enabling space' (Freund, 2001) was a slow one as the results of segregation had a profound influence on the self image of disabled people (as evidenced above). However, it was this very segregation that led to disabled people seeing themselves as having an identity separate from non-disabled people. Wood, interviewed for Campbell and Oliver's book states, 'The definition of issues and the identity of ourselves as people distinct in society, in a unique position in society, has got to be the key success...Discovering our identity as disabled people is very, very important' (Campbell and Oliver, 1996, p. 124).

It was the formation of a 'distinct' identity rather than the identity of being 'deficient' or 'tragic' that led to disabled people believing that they should be included in society and in order to achieve this, they needed to challenge non-disabled people's ideologies, including their view of economics. Maggie and Ken Davis, two disabled adults talk about the need for disabled people to be 'mobilised'. They state that with the development of technology and wealth in Britain, there was no longer any 'need' for disabled people to be segregated (Campbell and Oliver, 1996, p. 62).

Oliver and Barnes's (2012) view of identity is that it is formed through how other people define and respond to us as well as the 'cultural and material context in which

this construction takes place' (Oliver and Barnes, 2012, p. 110). I discussed in Chapter Two Foucault's writing about the gaze and how doctors defined forms of diseases (Foucault, 1989). Power can be seen to be working in the same way here. Identities are formed through medical classifications and cultural responses to this. As Oliver and Barnes write, factors such as the actions of others, inaccessible environments and segregation mean that people grow up with a 'disabled identity' which often results in 'internalised oppression' (Oliver and Barnes, 2012, p. 111). Oliver and Barnes (2012) discuss how disabled people have been the subject of negative images throughout history in the western world through 'dominant cultural images'. Although Oliver and Barnes acknowledge that there are attempts in the media to present more positive images of disabled people, they maintain that these present 'the acceptable face of impairment rather than the reality of disablement...' (Oliver and Barnes, 2012, p. 106). Some disabled people have 'self-identified' as disabled people to gain a more positive cultural identity through the 'politics of difference' (Oliver and Barnes, 2012, p. 171). As Gilson et al (1997) write, 'A confident, positive disability identity within a broad, inclusive disability has emerged. The benefit to disabled people to determine and relate their own stories is evident' (Gilson et al, 1997 p. 16).

Using the spatial metaphor, they have tried to establish for themselves a new cultural and political space. What is central to this is implicit in Gilson et al cited above and that is the issue of control. Disabled people have felt that they were able to tell their own stories rather than them being told from the perspective of a 'disabling' society. This is only true for some disabled people as many have not connected with any political movements or with a positive disability identity (Oliver and Barnes, 2012; Shakespeare, 2006). However, for those for whom this is true, there have been positive benefits of creating a new space in which disabled people can unite and gain a common understanding of their experience which is contrary to the dominant ideology of the society in which they live.

## **6. Who can occupy this disabled space?**

In the disability movement, the role of non disabled people, professionals and experts should be to support disabled people 'to take the lead in their own emancipation' (Campbell and Oliver, 1996 p. 62). Debate occurred about whether non-disabled people should be able to join some of the new organisations which were emerging within the movement. The Union for the Physically Impaired Against Segregation (UPIAS) decided that they would exclude non-disabled members. Vic Finkelstein gives a rationale for this:

Before you can develop a clear understanding of disability, the group most concerned needs to address it and look at it and understand it. When that's done, then others can come in. But if you bring others in before you've done that, then because the group is an oppressed group, it will have less experience and less capabilities than the other people who have come in, and they will modify it on their own terms (Finkelstein, 1996, p. 67).

Disabled people did not want the space they had fought to develop in the disability movement populated by non-disabled people who might well attempt to achieve what Gosling, speaking from a service user perspective, calls 'colonisation' (Gosling and Martin, 2012, p. 15).

## **7. Application to my own research**

In this research, I planned to be a part of a group with adults with Asperger's syndrome and I wanted them to be able to give their insights from the perspective of adults with Asperger's syndrome. I would form the group, so had initial control over it. The co-researchers had not had the opportunity to form as a group prior to the research; indeed, they did not know each other. I wanted to co-create with them a space in which they could work and express their opinions. I did not want this to be a space in which they experienced oppression. I did not want to 'colonise' the group. Although this will be discussed at greater length in the chapter on participatory research, it is worth noting here my position after reading the literature around this

issue. Dewsbury et al (2004, p. 154) discuss assertions that non-disabled people should not conduct research with disabled people in the same way that some writers assert that only women can conduct research with women. They call these stances 'standpoint epistemologies'. They state that the assumption that a non-disabled researcher cannot understand the culture of disabled people is not a research finding, but an *a priori* assumption. This is an important point and relates to the discussion in the chapter on Asperger's syndrome. The objection raised by Finkelstein as cited above and alluded to by Dewsbury et al is based on the perceived threat of non-disabled people (be they activists or researchers) either not understanding or not respecting the culture of disabled people. This is rather like early colonialists who wanted to reproduce their own cultures in other countries and did not respect the indigenous culture (Bartlett, 1994). This discussion strengthened the need for me as a researcher to try to understand the culture of the adults with Asperger's syndrome who were to be my co-researchers. This meant that I had to consider together with them how we could co-create our research space to be compatible with the way they think and act. We had to be mindful of the history of disabled people within the disabled people's movement and how they had been compromised at times by non-disabled people as I will now outline.

## **8. What has happened to this space?**

What happened to the space of the disability movement is a cautionary tale. Oliver has written two editions of 'The New Politics of Disablement', the first in 1990 and the second with Barnes in 2012. They reflect on their view (as disabled academics) of what has happened in the disability movement in the time between the two books being written. In the second edition, they point to what they see as the unchanged view of disability, in spite of the work of the disabled people's movement. They state:

Although there has been a radical reappraisal of the meaning of disability by disabled activists and some academics across much of the developed world

since the 1960s, disability is still regarded as primarily a health issue by politicians, practitioners and the general public (Oliver and Barnes, 2012, p. 11).

Oliver and Barnes write that the initial optimism that surrounded the achievements of disabled people in the disability movement has 'ebbed away' (Oliver and Barnes, 2012, p. 159). This they think is due in part at least to the choice of the movement to pursue a 'rights route to emancipation and equality'. As a result of this choice, individual disabled activists spent their time and energy in mainstream politics as they thought this was the most effective way of exerting influence. The result has been 'a strident re-affirmation of capitalist hegemony at the global level and the introduction of drastic cuts in state-sponsored welfare with a particular emphasis on services and support for disabled people...' (Oliver and Barnes, 2012, p. 159).

Oliver and Barnes also think that the views and ideas of disabled people have been 'adapted and adopted' by 'successive progressively right-wing governments' and big charities who have 'usurped' the language of the disabled people's movement and promised much but 'delivered relatively little' (Oliver and Barnes, 2012, p. 156). Morris (1991) wrote of disabled people joining organisations *for* disabled people, rather than *of* disabled people. She wrote that this happened 'predominantly because their class position leads them to fear radical change' (Morris, 1991, p. 177). Writing two decades before Oliver and Barnes, Morris wrote of a 'sense of outrage' regarding how some disabled people 'are used to give legitimacy to the organisations which do so oppress disabled people' (Morris, 1991, p. 177).

It seems that the early warnings in the literature in the discussions about whether to allow non-disabled people to join some of the organisations have proved prophetic. Oliver and Barnes comment that many disabled people who ten years previously would not have joined the big charities *for* disabled people rather than *of* disabled people have now chosen to do so. To understand what Oliver and Barnes are saying has happened, using a spatial metaphor, it appears that disabled people have left the

space that they formed for themselves and joined that of non-disabled people. From the perspective of Oliver and Barnes as disabled academic writers, the result has been that the very language of disabled people has been adopted by non-disabled people and the meaning behind it has been lost. The messages and ideas moving from the disabled space to the non-disabled space meant that the message of the disabled people's movement has not only been compromised but their own language has been used to achieve this. (Not all disabled academics accept this analysis as will be discussed later in this chapter). Oliver and Barnes cite Oliver's phrase 'disabling corporatism' as a way of describing the 'changing landscape of disability politics' (Oliver and Barnes, 2012, p. 156). Gosling, writing in Gosling and Martin (2012) talks of the '*incorporation*' of service user organisations (Gosling and Martin, 2012, p. 14). She speaks of her experience of working in a service user advocacy group where large organisations have asked for the involvement of the group. She discusses 'how the very language, ideas and energy of popular movements had been sucked into the organisational machine, but with all the gristy bits spat out and the residue scarfed back out to us in a bland, diluted and narcotic mush' (Gosling and Martin, p. 14).

These cautionary messages in the literature have real relevance for this research. My goal was to co-create a space with adults with Asperger's syndrome and for us to work together in such a way that the whole group would take part in every stage of the research. I wanted to find a way of working together with them that enabled their views and experience of Asperger's syndrome to inform how the research was conducted, including the data analysis. I particularly wanted the data to be analysed in a way that did not just interpret what the participants said from a neuro-typical perspective but captured the autistic perspective of it. The literature has made me very aware of how voices can be silenced through very subtle means and that means can often be 'inclusion' itself. How to avoid this happening in this research was a key consideration for me. I was also aware, as discussed in the chapter on the literature on Asperger's syndrome, that I had to try to facilitate an 'autistic space', one in which the participants would be comfortable to contribute. The challenge seemed quite daunting

but I was convinced that the awareness of these issues was the first step to finding a way to working together which would be *enabling* rather than *disabling* in the co-creation of an *enabling space*. It was the social model of disability which I thought held the key to working in an enabling way with the group. There are other examples of research in which enabling spaces were co-created (Gillard and Turner, 2010) and this will be discussed in Chapter Four. These spaces are called ‘co-produced’ by the people who were involved in the research and I have adopted this language throughout as this best describes how I aimed to work with the co-researchers. I will also discuss why we were successful in this co-production in the methodology section.

### **9. The social model of disability as an influence on this research**

As I stated in my introduction, I was very influenced as a social work practitioner by the writings of Michael Oliver and his formulation of the social model of disability. It was this model that shaped my understanding of how the world operates in relation to disabled people. I had seen for myself how many disabled people accepted what has been termed ‘the medical model of disability’ (Oliver, 2009) and the literature discussed above has demonstrated how this has happened. The understanding of disability has come to be dominated by it being seen as individual ‘tragedy’ (Oliver and Barnes, 2012). In the literature I read there has been a lot of emphasis on physically disabled people, although Oliver and Barnes acknowledge that they were criticised for this in their first edition (Oliver and Barnes, 1990) and state in the 2012 edition (Oliver and Barnes, 2012) that the social model applies equally to people with cognitive impairments or ‘learning difficulties’ as they term them. A number of other writers have also criticised the social model for mainly applying (or being applied to) people with physical impairments (Dewsbury et al, 2004; Goodley, 2001). Goodley is particularly critical about the omission of people with a learning disability and agrees with Chappell (1998) who he quotes as writing that people with a learning disability have been ‘left in the cold’ (Goodley, 2001, p. 211). I could not find any references in the literature that mentioned people with Asperger’s syndrome when the social model of disability is discussed. This may be because autism, as we have seen in Chapter One is framed as a medical or psychiatric issue rather than as a disability. Part of my



motivation for undertaking this research was to explore the relevance of the social model of disability to people with Asperger's syndrome. I was starting from the assumption that it was applicable. I next want to examine what the literature says about the social model of disability. I will discuss it in terms of definition and criticisms of it. I will also discuss the implications of the model for my research.

### **10. What is the social model of disability?**

The evolution in thinking that gave rise to the development of the social model of disability led to a critique by Barnes and Mercer (2012) of the term 'the disabling society'. They cite a book edited by Paul Hunt (1966) entitled *Stigma: The experience of disability* in which twelve disabled people write of their experiences regarding how they were viewed by society. Barnes and Mercer cite Hunt: 'the problem of disability lies not only in the impairment of function and its effects on us individually but more importantly in our relationship with "normal" people' (Barnes and Mercer, 2010, p. 28). Hunt argued that disabled people are regarded as 'unfortunate, useless, different, oppressed and sick', and that they are set apart as being 'abnormal'. He thought that non-disabled people regarded disabled people as such because their own fears were stimulated by them as well as 'their failure to accept themselves as they really are, and the other person simply as 'other'' (Barnes and Mercer, 2010, p. 28). This was the beginning of what Hunt states as an aim to break free from a system 'dominated by condescension and patronage on the one hand and inferiority or deference on the other' (Barnes and Mercer, 2010, p. 29).

In the 1960s and 1970s, when disabled people reflected on their experience of living in society, they began to focus more on how society was organised rather than the effects of their own impairments. They started to think that their difficulties were the result of living in a society which did not accommodate them rather than looking at their differences or impairments as the cause (Barnes and Mercer, 2010). The identification of impairment with disability was challenged with new definitions proposed. In 1976 The UPIAS (The Union of Physically Impaired Against Segregation)

defined impairment as 'lacking part or all of a limb, or having a defective limb, organ or mechanism in the body' and disability as:

...the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities (quoted in Barnes and Mercer, 2010, p. 30).

The obvious focus on physical impairment was subsequently changed to accommodate people with other impairments (Barnes and Mercer, 2010). Oliver (2009, p. 44) cites another document produced by the UPIAS (Fundamental Principles of Disability, published in 1976) as the source of what caused him to rethink his own experience as a disabled man and from that arose the social model of disability. He cites his own position very clearly: 'Most illnesses are treatable and even curable by medical interventions; most impairments are not curable; and all disability can be eradicated by changes to the way we organise society'.

Oliver was the disabled academic who proposed the social model of disability as a way of understanding how people with impairments are disabled by society. It is referred to in the literature as the British social model as the versions used in other parts of the world are seen as less 'extreme' in that they are not as clear in their separation of impairment and disability (Shakespeare, 2006). Oliver and Barnes summarise what the social model of disability does in one sentence, 'This social model breaks the causal link between impairment and disability' (Oliver and Barnes, 2012, p. 22).

They state that the model is not based on the denial of the existence of impairments, but that it is not these that cause disabled people's 'economic and social disadvantage' (Oliver and Barnes, 2012, p. 22). The model emphasises the way in which society restricts disabled people's opportunities, both socially and economically and creates dependency. It is not impairment that 'disables', but society. They cite Finkelstein's redefinition of disability as 'the outcome of an oppressive relationship between people

with impairments and the rest of society' (quoted in Oliver and Barnes, 2012, p. 22). The social model shifts attention away from impairments to what disabled people experience in common from a disabling society and highlights areas which should be challenged.

The importance of the social model is difficult to quantify. It has led to a change in policy and provision. Roulstone and Prideaux (2012) refer to it as 'the conceptual glue' for policy change (Roulstone and Prideaux, 2012, p. xv). Although they acknowledge that it is a 'moot point' about how much it has 'truly penetrated policy', they write that it is almost impossible to understand 'the growth of self-directed support and personalisation ideas without the social model of disability with its focus on choices and rights and its emphasis on giving disabled people tools to overcome established barriers' (Roulstone and Prideaux, 2012, p. xv). However, the social model does have its critics, as will be discussed now.

#### **a) Criticisms of the social model and implications for this research**

The social model has been heavily criticised by some disabled academics, in particular Shakespeare (2006), who was initially a supporter of the model. He fundamentally disagrees with Oliver's view that the demise of the disabled people's movement is the result of disabled people's ideas being subsumed into mainstream politics and instead cites the social model itself as being the cause. Crucially for this research project, Shakespeare states: 'The social model of disability which has successfully inspired generations of activists has largely failed to produce good empirical research, because it relies on an overly narrow and flawed conception of disability' (Shakespeare, 2006, p. 9). Shakespeare thinks that the social model is based on the 'false dichotomies' of impairment and disability. He states that there is no work anywhere that actually proposes a 'medical model' and the portrayal of it by social model proponents builds up a 'straw man' (Shakespeare, 2006, p. 18). The medical model is more about 'symbolism than actual content' (Shakespeare, 2006, p. 18) and it has come to stand for research about disabled people that is done without their involvement, the

dominance of professionals, the 'idea that disabled people are defined by their physical or intellectual deficits' and it stands for 'medicalisation' (Shakespeare, 2006, p. 18).

The heart of Shakespeare's disagreement with the social model of disability is concerned with the relationship between disability and impairment. He states: 'There can be no impairment without society, nor disability without impairment' (Shakespeare, 2006, p. 34). The difference between the two positions is concerned with the collective experience of disability and the individual experience of impairment. The distinction between collective and individual participation is made by Fleming (2012) and this is a useful distinction to make in this context. All disabled people experience disabling barriers but they have individual experiences of impairment. However, in Shakespeare's view, impairments cannot be separated from disabling barriers, as disabling barriers would not exist without the existence of impairments. In Shakespeare's view, impairments are the cause of much pain and inconvenience to disabled people but the effects of them are exacerbated by disabling barriers. He cites some feminist writers who abandoned the 'dangerous dualism' of social gender and biological sex. This, according to Shakespeare, has led to a helpful comparison in thinking about disability. In the social model, impairment is understood as being biologically based whereas disability is socially based. He makes the point that this duality might be easy to perceive theoretically or politically, but is very difficult when applied to qualitative research 'because it is hard to separate impairment from disability in the everyday lives of disabled people' (Shakespeare, 2006, p. 36). He cites a number of research studies which have shown the 'interpenetration of impairment and disability, rather than simply showing the social model perspective' (Shakespeare, 2006, p. 37). One example that he cites is of Helen Lester and Jonathan Tritter's research with people with 'serious mental illness': 'while the authors endorse a social model perspective, their data shows that respondents found it impossible to ignore their impairment' (Shakespeare, 2006, p. 37). Shakespeare concludes:

My interpretation of these research studies is that they show the interpenetration of impairment and disability, rather than simply endorsing the social model perspective. In fact, I would argue that any qualitative research with disabled people will inevitably reveal the difficulty of distinguishing impairment and disability (Shakespeare, 2006, p. 37).

I disagree with Shakespeare's assertion here. It is my position that it is possible to distinguish between impairment and disability. For this research this means acknowledging the different ways that people with Asperger's syndrome think and conceptualise (if this equates to an impairment) and creating a research space which does not replicate the disabling barriers of society. If a research space is co-created which does not disable, then it is possible to see if the co-researchers are able to work together in a way that they would find difficult in a neuro-typical space. However, as a researcher, there are lessons that I can take from this debate. It teaches me that it is important to remember the lessons from history about how disabled people were physically excluded and that the social model perspective gives insights into the experience of disabled people still being excluded by society. Shakespeare's arguments are a reminder that each disabled person has their own unique experience as well as their own differences arising from their impairment. In co-creating an enabling space for the research to take place, we need to consider both of these. Indeed, it has already been stated above that Oliver does not deny the existence of impairments, a fact which Shakespeare acknowledges but the emphasis of Oliver's work (and that of other British disabled academics who favour the social model of disability) is certainly concerned with the role of disabling barriers, rather than impairments. According to Freund, Oliver does in fact deliberately overstate his position to emphasise the role of society rather than impairment in disability (Freund, 2001).

Shakespeare discusses Oliver's account of why disabled people are often unemployed and states that there are some disabled people who are unable to work as a result of their impairment rather than societal barriers, a fact that Oliver does not concede. He

pursues the concept of removing all barriers for disabled people and cites disabled people who state that the removal of barriers does not ameliorate their impairment. Shakespeare also states that to remove a physical barrier for some, such as lowering the curb for wheelchair users, actually creates a barrier for others, for example visually impaired people who may not be able to distinguish the edge of the pavement from the road. This for me highlights the importance of considering individuals, as I acknowledged in Chapter Two in relation to how people with autism are different from each other. It does not invalidate the social model of disability. However, the dangers in separating a consideration of impairment and disability are highlighted by Morris (2011) in what she calls a 'blatant corruption of the social model of disability' (Morris, 2011, p. 6). Morris discusses the new assessment framework intended to replace Disability Living Allowance. She states that the government has interpreted the social model of disability in such a way that it is a potential '(mis-)use' (Morris, 2011, p. 6) as the new framework maintains that if a person is mobile, with the aid of a wheelchair, then they do not meet the criteria for benefits under the new system. This argument is based on a separation of disability and impairment as implicit in it is the assumption that 'using aids and adaptations "successfully" makes people 'independent' ' (Morris, 2011, p. 6). Morris also highlights the fact that there has generally been a tendency in disability policy to minimise the effects of physical and mental ill health (Morris, 2011, p. 7). Morris is clearly an advocate of the social model of disability and sees this false separation as a misuse of the model.

Shakespeare (2006) also discusses the concept of an identity of disability. He thinks that the social model underpins identity politics and asserts that it is a 'powerful way of denying both the relevance and the negativity of impairment' (Shakespeare (2006, p. 80). It is a way of boosting self image as it leads to an identification with other disabled people and a belief that it is society that causes the problems that disabled people encounter, rather than their impairments. Shakespeare refers to the 'prison of identity politics' as he believed strongly that it is preferable to seek what they have got in common with non-disabled people, 'promoting inclusion and equal status, not

separatism' (Shakespeare, 2006, p. 82). He states: 'The goal of disability politics should be to make impairment and disability irrelevant wherever possible, not to seek out and celebrate a separatist notion of disability pride based on the ethnic conception of disability identity' (Shakespeare, 2006, p. 82).

The insistence that the disability/impairment duality is a false and even 'dangerous' distinction is I think unhelpful. It seems self evident that disabling barriers could not exist without impairments and I have not read anything in the literature that denies this. What is helpful about the re-consideration that Shakespeare provokes is that it reinforces the necessity for an understanding of 'impairment' (as he and Oliver term it). It is completely impossible to identify, let alone seek to remove disabling barriers without understanding the nature of the needs of individuals arising from their impairments. Shakespeare's own example of the curb lowering serves to illustrate this point. It is necessary to understand that people with visual impairments need a clear physical indication of boundaries in order to keep themselves safe. It is true that many physical environments are not organised for people with visual impairments, but it is also true that an understanding of the impairment as well as that of the physical environment needs to be gained in order to meet the needs of visually impaired people in the community. The two need to go hand-in-hand in order to start to address disabling barriers but they both need to be understood. The social model of disability proposes that barriers arise in society as it is organised by and for non-disabled people. Shakespeare seems to be saying that the barriers arise from the nature of people's impairments. This seems a matter of semantics rather than a weakness of the social model of disability. However, it is a concern which is echoed in the writings of other disabled academics. Thomas and Corker (2002) cite indebtedness to Oliver and other proponents of the social model for emphasising the role of the environment, but state:

In their attempt to distance themselves completely from the 'impairment causes disability' stance of the individualistic or medical model of disability, most social modellists have paid insufficient attention to the ways in which

different forms of impairment come to be associated with different forms or manifestations of disablism (Thomas and Corker, 2002, p. 20).

They write that it is important to take into account what they call *impairment effects*. 'These are the direct effects of impairment which differentiate bodily functioning from that which is socially constructed to be normal or usual' (Thomas and Corker, 2002, p. 20). Thomas and Corker think that it is the interaction of impairment effects and disability which 'profoundly shape' the lives of what they term 'people with impairments' (Thomas and Corker, 2002, p. 21). On the basis of this view, they propose an alternative definition of disability: 'a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being' (Thomas and Corker, 2002, p. 20).

This definition takes account of oppression and disabling environments but also recognises the effects of this oppression on the disabled person. It still separates disability and impairment, which is in line with the social model of disability. What Thomas and Corker bring in addition to the perspective of the social model is the impact on the disabled person of both disability (at the hands of a disabling society) and the effects of their impairment. It brings together the collective as well as the individual experience. This seems a less political definition as it has at its centre the experience of disabled people. However, given the feminist mantra that 'the personal is political' (Hanisch, 1969), this emphasis is not incompatible with a political element, which is the concern of the social model. Thomas and Corker's writing discusses 'impairments', which does not sit very comfortably with the concept of 'differences'. *Impairment effects* does suggest a deficit model of thinking based on physical, sensory or cognitive impairments. *Difference effects* might be more in keeping with a difference rather than a deficit model but needs to be balanced with *sameness effects*. Without a consideration of what it means to be neuro-typical, any model which concentrates on the 'effects' of a difference always seems to emphasise the 'Other'.



This seems almost unavoidable in a society which is dominated by people who are neuro-typical but it needs to be borne in mind as this is just one perspective. The relevance for this research of Thomas and Corker's work is the emphasis on the experience of disabled people. It seems that the interplay between people's experience as a result of their difference and their experience as a result of oppression both need to be borne in mind, the collective as well as the individual experience. The two are interlinked as they both form the experience of disabled people. The issue in relation to difference for people with Asperger's syndrome is that difference or *impairment* is not in the way that their bodies physically function, but in the way that their minds work. It is difficult to find such a clear distinction between *impairment/difference effects* and experience of oppression. It is the gulf in the way that people with Asperger's syndrome experience the world and how neuro-typical people experience it, along with the fact that it is neuro-typical people who organise the world that causes people with Asperger's syndrome their difficulties and anxieties. The interconnectedness between the environment and the disabled person and the disabled person and other people is emphasised by Price and Shildrick (2002). They criticise the social model for denying the relevance of the 'body as such to *disability*', which they say is in contrast to impairment, which is located in the body (Price and Shildrick, 2002, p. 63). Price and Shildrick are a writing partnership of a disabled and a non-disabled woman, which they state is a deliberate choice to challenge the view that only disabled people can understand the experience of disabled people. They state:

It is as though there is a reluctance to acknowledge that someone without evident disabilities could have anything useful to say, or at the most that her role is subsidiary. So we want to ask what is going on here, and why it is relevant to the whole question of how disability studies might forge a more fruitful relationship? (Price and Shildrick, 2002, p. 64).

They draw a parallel between approaches to race and to disability, where the way the concept of *whiteness* is constructed is crucial to the understanding of racial otherness.

They state that in a similar way, 'disabled' and 'non-disabled/able-bodied' are constructed in mutual relation. They conclude that this means the way of understanding disability should be a joint one, between disabled and non-disabled people.

Two models of understanding disability that have developed outside of the UK also emphasise how disability is constructed. There is a conceptual tension between these two models. The cultural model examines how disability is constructed and can only be understood in relation to 'normalcy' and the relational model proposes that disability is a 'relative' construct, created through a mismatch between the person and the environment and so disability is a 'situational or contextual phenomenon' (Goodley, 2011, p. 17). The cultural model of disability was proposed by North American disability studies. Scholars associated with this model reject the distinction between impairment and disability because as Goodley (2011, p. 14) explains, 'they view biology and culture as impinging upon one another.' Goodley (2011, p. 14) cites Ware (2009) as interpreting the cultural model as shifting thinking from 'viewing bodies as bad (biological determinism and medicalisation) to 'thinking about bodies' (socio-cultural analysis). Writers from a cultural model perspective have shown how disabled people are not excluded from culture, but are understood through cultural practices, such as metaphors for evil or unviability and as Goodley (2011, p. 15) comments, 'Disability is used by popular culture to uphold dominant ideas as the crutch upon which narratives (and cultural practices) lean for representational power.' This model of disability is applicable to this research, but it does not go far enough in its analysis of culture. It is not merely how people with Asperger's syndrome are represented through culture that is of concern but how they are excluded from a culture that is primarily created for and by neuro-typical people.

The relational model has more applicability to this research. This model was developed in Nordic countries and has Normalisation as one of its principles. Goodley (2011, pp. 17-18) outlines both its moral implications and its 'negative effects'. The

moral implications are that 'Disabled people are excluded from communities, services and professional practices because of a mismatch of expectations, biological needs and environmental opportunities.' The 'negative effects' are a 'lack of distinction between impairment and disability' which 'might re-assert a medicalised view of the disabled body and mind'. The relational model is applicable to this research as it emphasises the 'mismatch' between the individual and the community. However, the model is grounded in normalisation, which is based on principles of inclusion and allowing people with a learning disability the chance to live a life as close to 'normal' as possible (Wolfenberger, 1972). What is problematic about the concept of Normalisation is that it valorises the 'normal'. There is indeed a 'mismatch' between people with Asperger's syndrome and the environment. As Goodley states, it is based on the concept of disability being a 'relative construct' based on this mismatch. This is a helpful concept in that it does address the exclusion of people with Asperger's syndrome from society. However, the lack of distinction between impairment and disability means that this perspective, which is offered by the British social model is lost. It is the separation of impairment and disability which allows for the analysis of difference i.e. 'impairment', and the treatment and exclusion of people with a difference, i.e. 'disability'. The relational model's underpinning by the concept of Normalisation and its valorisation of the 'normal' are at odds with the principles behind this research as the ability to value difference is impaired by such a philosophy. Although the relational and cultural models of disability offer insights that are valuable and relevant to this research, it is the British social model of disability was the most appropriate.

Another criticism of the social model relates to the role of experience. Dewsbury et al (2004, p. 146) go as far as saying that the social model can in fact be 'profoundly 'anti-social''. The authors write that the social model of disability can 'ironicize' the experience of disabled people as they have a 'flawed' understanding of what is really going on so they need a 'sociological remedy'. On the other extreme, according to Dewsbury et al, it can 'privilege' versions of disabled people's experience which

attends to 'socio-political matters, but which leave the ordinary practical business of getting on with one's life unattended to' (Dewsbury et al, 2004, p. 146). These criticisms are interesting and they do draw attention to how the social model could be used in an oppressive way. This, I consider to be another 'misuse' of the model. The social model was created to separate impairment and disability, showing that it is society that disables, not the impairments. It was not conceived of to provide a sociological remedy but to demonstrate how people with impairments are disabled by society. The remedy was not sociological but political. It was not designed to 'ironicize' the experiences of disabled people any more than feminism is designed to 'ironicize' the experiences of women. It requires changes in the organisation of society. It should not leave disabled people to get on with the 'practical business' of their lives alone, but provides a framework in which their experience can be understood and disabling barriers challenged. However, what it demonstrated to me was the importance of how I discussed the social model with the group. I had to consider the impact of what I said and how it related to them and ensure that I was not providing a 'remedy', but rather if the situation arose, facilitate a discussion about their experiences that explored other ways of understanding them. I also had to ensure that I did not encourage the framing of their experience in such a way that the everyday experience of their lives was not valued. It was indeed, the everyday experience of their lives that I hoped would contribute to richness of the research.

#### **b) Reactions from social model proponents to its criticism**

There is a strong rebuttal from those who advocate the social model of disability that they deny the impact of impairment. Finkelstein (2001), a leading disabled activist, states that the choice of understanding disability for disabled people was:

- either our tragedy is that the impairments we possess make us incapable of social functioning, or
- our society is constructed *by* people with capabilities *for* people with capabilities and it is **this** that makes people with impairments incapable of functioning (Finkelstein , 2001, p. 1).

He states that the position of the UPIAS was that: 'although it may be a *tragedy* to have an impairment, it is *oppression* that characterises the way our society is organised so that we are prevented from functioning' (Finkelstein, 2001, p. 1). Finkelstein separates the 'personal tragedy' of acquiring an impairment at a personal level from the oppression that disabled people face at a social level. Implicit in this is an acknowledgment of the difference between individual and collective experience discussed earlier in this chapter. Finkelstein strongly denies that the disabled people's movement has not been interested in the way that impairments affect people, but rather decided to concentrate on how society disables. He explains that models do not explain everything but provide ways of seeing the world in different ways. The social model 'has provided the disability movement with an invaluable tool which has strengthened our insight into the struggle for emancipation' (Finkelstein, 2001, p. 3). It is not that the social model of disability does not recognise impairment, or even impairment effects. Rather it is a political choice to emphasise the disabling effects of society. Finkelstein's explanation does not take account of difference as opposed to impairment. It seems that differences such as those of people with Asperger's syndrome are not at the forefront of this dialogue.

Oliver (2009) devotes a section in his book 'Understanding Disability: From Theory to Practice' to answering criticisms of the social model. He states that criticism that it does not take into account the 'reality' of impairment is based on a misunderstanding of the model. In a clear statement about the distinction between the individual and collective experience of disabled people, Oliver writes that it 'is not about the personal experience of impairment but the collective experience of disablement' (Oliver, 2009, p. 48).

Oliver also answers criticisms that the social model does not take account of the physical pain of disabled people: 'I cannot accept the assertions that the social model is not based upon disabled people's experiences. Quite the reverse, it emerged out of the experience of disabled activists in the 1970s' (Oliver, 2009, pp. 48-49).

It seems that what is at the heart of the criticisms of the social model is that it ignores the experiences of disabled people. This is ironic (as Oliver points out) as it was proposed as a result of the experiences of disabled people. The emphasis before the social model was proposed, and before other disabled people such as Hunt began to challenge societal attitudes, was to blame actual impairments for people's difficulties. What the social model and the writing of its proponents have done is to challenge this and to highlight the difficulties which society, by the way it is organised, presents to disabled people.

### **c) Conclusion on how the social model of disability is relevant to this research**

The literature has been very thought provoking in relation to the social model of disability. My original motivation for completing this research was to apply the social model of disability to people with Asperger's syndrome and create an 'enabling space' in which they could participate in research. That motivation remained but the literature has made me think of the dangers of placing the emphasis on the disabling society alone. Impairment or difference and disability do seem to be two concepts which cannot be understood without the other and an attempt to do this result in a partial and ultimately unhelpful view. They need to be understood in the context of individual and collective experience. A consideration of both will result in an understanding of the impact of society on people with these differences. In order to understand difference, a concept is also needed of what it is to not be 'Other'. The social model's separation of disability and impairment was for 'pragmatic' purposes. Proponents of the social model resist research into the experience of impairment because they fear it would reinforce a 'personal tragedy' view of disability (Barnes and Mercer, 2010). For this research, I need to have an understanding of what it is to be neuro-typical as it is this understanding that I take to the research in the same way that it is the understanding of what it is to have Asperger's syndrome which the group members bring. The social model has provided me with the understanding of how disabled people are oppressed and this remains as a key understanding in trying to create an 'enabling space', but this has to be complemented by an

understanding of difference and the impact that this might have on people. The enabling space which I hoped to facilitate for the group of adults with Asperger's syndrome would need to be one in which differences were recognised and acknowledged in relation to neuro-diversity but more than that, the results of the differences accommodated. The literature I have referred to in the previous two chapters also complements the learning for my research. From that learning, I add to the desire to create an enabling space the awareness of what might constitute an 'autistic space' and the awareness that this might look different for different individuals with Asperger's syndrome.

In the next chapter, I will discuss participation and participatory research. I examine the literature and apply it to my own research and explore the remaining concepts which helped me plan and evaluate the research. I will also discuss what the literature says about working with disabled research partners to inform my thinking about co-creating the enabling space in which the research could take place.

## **Chapter Four**

### **Literature IV: Participation and Participatory Research**

In this chapter, I will explore the literature about participation and about participatory research and from this discussion draw out the characteristics of the type of research space I wanted to create in which to co-produce this research. Having previously discussed the literature concerning Asperger's syndrome, disability and the social model of disability using spatial metaphors, I will continue to use 'space' in my discussion of participation and participatory research. When referring to a 'space' in this chapter, it is once more a metaphorical space. It is the space of participation; the space that is the sum of interactions between service users and the researchers or organisation which has 'invited' their participation, whether that be in relation to services or research activities. Using a spatial metaphor in understanding participation brings insights that might otherwise be lost. As the participatory space is one where service users (and carers) and professionals interact, it focuses on the roles of all parties and so leads to questions about the experience of all rather than one. To differentiate between the working together which took place and the work that was produced together, I have chosen to use the term 'co-produce' when referring to research and 'co-create' when referring to a research space.

This chapter will be in two main parts, the first relating to the nature of participation in general and the second specifically to participation in the research process. In the first section I will explore the literature concerned with participation and differentiate it from 'involvement' by examining how these concepts are defined. I will explore the motivation behind participation, ways this can be achieved and the consequences of participation. When referring to what authors have said, I will use their choice of terms in relation to 'participation' or 'involvement', although I will use the term 'participation' myself. This discussion will be captured under the following headings:

1. What is participation?
2. Why co-create a participatory space?
3. How service users experience a participatory space



#### 4. Barriers to the development of a participatory space

In part 1, I will concentrate on what the literature says about the role of organisations in co-creating a participatory space. In part 2, I will focus more on the role of the service user in co-creating a participatory space. I will also explore the literature in relation to participatory research, emancipatory research and co-produced research, discussing what a 'research space' might look like in each. I will address these discussions under the following headings:

1. Participatory and emancipatory research spaces
2. Another look at emancipatory research
3. Co-created research space
4. Interrupted space
5. Implications for my research

I will refer to 'service users' in this chapter, whereas in previous chapters I have used the term 'disabled people' as this reflects the language used in the literature.

### **A note about power**

In this chapter I will refer to power and empowerment throughout. Power is not simply transmitted from one person to another as its operation is complex. As already discussed, a Foucauldian view of how power and knowledge are linked underpins my understanding of the operation of power. Power is also multi-dimensional, operating through various levels of influence as well as different forms of influence and through families, communities, as well as nationally and internationally (Domenelli, 2002). These different sites of power interact with each other and as Smith writes, 'Although all social interactions are played out within this framework, specific elements will vary in the degree of influence they exert' (Smith, 2008, p. 62).

In this thesis I am concerned with specific operations of power, but acknowledge that there are other influences that could be accounted for in relation to adults with Asperger's syndrome. I discussed in Chapter Two how Foucault linked power and

knowledge and in Chapter One how the discourse around Asperger's syndrome has been created by neuro-typical people. It is these specific operations of power that I am addressing by a reconsideration of the discourse concerning Asperger's syndrome and using the social model of disability to recognise the barriers which are in place within society for people with Asperger's syndrome. Lukes (2005) discusses how cultural practices as well as social structures can suppress some conflicts while mobilising others and power can operate through what is not done as much as what is done in what he refers to as the 'third dimension of power' (Lukes, 2005, p. 26). This aspect of power needs to be considered in the co-creation of the research space and in thinking about how my neuro-typical bias is not exerted to the detriment of the co-researchers. Smith (2008) recognises that practitioners are also subject to authority. It is in the interplay of practitioner identity, their standing and authority and their interactions with service users that the multiple sites of power all come together (Smith, 2008, p. 62). This is referred to as 'relational power' (Smith, 2008, p. 53) and this is the power that influences me as a practitioner both outside and inside the research space. It influences the interactions between myself and the co-researchers. The importance of this to my research is to acknowledge that I am constrained by University ethical approval procedures, timescales and my own identity as a qualified social worker as well as a researcher.

When I refer to power being shared in this chapter, it is in the context of the understanding that it is not simply a matter of moving it from one person to another, but is much more complex than that. Smith suggests an analytical framework for considering power:

- Understanding power relationships
- Exploring power relationships
- Reframing power relationships
- Changing power relationships (Smith, 2008, p. 150).

This is relevant to this research as the co-creation of an enabling research space relies on a careful consideration of these stages. Power relationships have to be understood

between neuro-typical people and people with Asperger's syndrome. This was the concern of Chapters One and Two and the relationship between disabled and non-disabled people, the concern of Chapter Three. This chapter is concerned with exploring power relationships and how they are discussed in the literature in relation to participation and participatory research. The co-creation of the enabling research space is concerned with reframing the power relationship between myself as a non-disabled, neuro-typical researcher and the co-researchers and changing the power relationship by co-creating an autistic enabling research space. It is to this discussion that I now turn.

## **Part 1, Participation**

### **1. What is participation?**

The participation I am concerned with in this chapter is in relation to influencing services and policy rather than where service users are involved in designing their own personal care provision, which is another area also discussed in the literature (Beresford and Carr, 2012). Brodie et al (2009) summarise the first type of participation as being about 'voice and choice'. Brodie et al characterise it as being a 'driver' for policy change and cite government rhetoric to this effect. The implication is that participation can give rise to a distinctive voice and influence services and policy even when this is operating within existing democratic structures. The purpose of a participatory space then is to influence and achieve change in the wider space of the organisation.

Participation, however, is a contested term and often used in different ways by different authors (Brodie et al, 2009). Some of the literature refers to 'participation' and some to 'involvement'. It is noteworthy that two books which were published recently on this subject both use the term 'involvement' in their titles (Barnes and Cotterell (eds). 2012 and Beresford and Carr (eds). 2012), although the latter book has authors who write chapters in it referring to participation and the former has authors who refer to participation in relation to research. Adams (2003) distinguishes between participation and involvement:

Involvement refers to the entire continuum of taking part, from one-off consultation through equal partnership to taking control. Participation refers to that part of the continuum of involvement where people play a more active part, have greater choice, exercise more power and contribute significantly to decision-making and management (Adam, 2003, p.31).

For Adams, rather than involvement and participation being about different activities, participation is a form of involvement and is determined by the exercise of choice and power on the part of service users. In this definition, participation is about the role that service users play, what happens in the space, how service users can exert influence and how the space relates to the wider organisational space.

Other writers choose to adopt 'involvement' as the term they use when discussing processes of involving service users in having a voice in decisions that are made about services that they receive, either individually or collectively. Barnes and Cotterell (2012) examine the term 'user involvement'. They emphasise the contested nature of the term 'service user' as well as 'involvement'. They discuss the negative implications of the term 'service user' or 'user' as people being defined through their relationship with services and the passive role it seems to imply. They state that they adopt the term 'service user involvement' to mean 'the involvement of people who receive or are eligible to receive health and social care services and their carers who may be family or close friends' (Barnes and Cotterell, 2012 p. xxiii). They explain that they recognise the limitations of this definition but choose it because of its 'broad descriptive utility.'

Spatial analysis is a way of measuring how power operates in a participatory space. However, the literature highlights that there are different versions of participation, stemming from different philosophies (Barnes and Cotterell, 2012) and these different philosophies affect the participatory space. According to Beresford and Croft (2001), much participation in research is about 'data extraction' rather than 'empowerment,

that is to say, increasing their personal and political power' (Beresford and Croft, 2001, p. 296). Barnes and Cotterell (2012) build on this argument and discuss the distinction between 'consumerist' and 'democratic' versions of involvement. 'Consumer' approaches tend to be where service providers see service users as being able to comment as consumers of services on their quality and suitability, whereas 'democratic' approaches embody 'ideals of participatory democracy, and is concerned with enabling people to have more control and influence over issues that affect their lives... [this] extends to enhancing the way people can collectively make changes to improve their situation' (Beresford and Croft, 2001, p.76).

Carr identifies the role of different approaches in determining how participation is viewed: 'Democratic initiatives involve service users influencing and making decisions at strategic levels, whilst consumerist approaches focus more narrowly on consulting people about services they receive' (Carr, 2004, p.5).

The definition that I will adopt is based on the Adams' definition (2003) but I will also take account of the points that Carr and Barnes and Cotterell make and will take a democratic rather than a consumerist approach. For this research, a participatory space is a metaphorical space which describes where service users play an active part in decisions made at a strategic level in relation to wider services rather than those that they receive individually. It is where service users are able to exercise power and make a difference to decision making. Essentially, a participatory space is a means to achieve change, rather than an end in itself.

Indeed, much of the literature tends to concentrate on evaluating 'process' rather than 'impact and change' (Carr, 2012, p. 45). This may be because impact and resulting changes are more likely to result if the conditions in the participatory space are conducive to participation. A participatory space is therefore important for a number of reasons:

- Firstly, how service users are treated in the participatory space establishes how serious the organisation is about the whole process.
- Secondly, how service users are treated in the participatory space gives a clear message to them about their importance and about who is allowed to have power and a voice in decision making processes.
- Thirdly, the participatory space can act as a model in relation to how service users can participate in the wider organisation. If they are marginalised in the participatory space, this gives a poor message to the wider organisation. Whereas if they are treated as participants in decision making and their perspective valued and listened to, this provides a good model to the wider organisation.
- Fourthly, the quality of the participatory space will affect the changes that result.

The question of whether it is the result or the process of participation which is the most important to the service users who take part is a debatable issue. For some, it is a political process understood in the context of the disability movement. As Charlton (2000, p. 3), a disabled activist writes, 'If we have learnt one thing from the civil rights movement in the U.S., it's that when others speak for you, you lose'. For Charlton, the context of participation is of 'a dependency born of powerlessness, poverty, degradation, and institutionalisation' which he writes 'begins with the onset of disability and continues until death' (Charlton, 2000, pp. 3-4). He states: 'For the first time in recorded history politically active people with disabilities are beginning to proclaim that they know what is best for themselves and their community' (Charlton, 2000, p. 4).

Others take a different view, for them what is important about participation is not the collective good achieved through political change, but the individual benefits they experience as part of the process. West (2004), an advisor for Save the Children UK asks the question about what engages children and young people in participation and concludes that this might be 'fun', engagement and learning. However, he concludes that 'this is not really enough: participation cannot escape its connection with power and thus with politics' (West, 2004, p. 23).

The motivation for wishing to be involved in participation reveals much about how both organisations and service users' view a participatory space. This in turn has influence over how the space is managed and how service users are treated in it as well as how they and professionals behave in it. Clearly this issue of motivation is an important one which has attracted attention in the literature and I shall now turn to a discussion of this.

## **2. Why co-create a participatory space?**

The literature indicates that the motivation to co-create a participatory space is different for different parties. I will examine this motivation as it pertains to, firstly, the joint motivation between service providers and service users, secondly the motivation from a service user perspective and thirdly the motivation from a service provider perspective. What the literature does not reveal is any motivation to co-create a participatory space for the purpose of creating other spaces, be they actual services or policy debates. The literature does not explore the learning from the relationships between service users and professionals that develop in participatory spaces -for example how this could be transferred and applied to the improvement of services.

### **a) Overlapping motivation from service users and service providers**

Improvement of services is the aim of participation which is claimed by both service providers and service users. However, it is worth noting though that service users and service providers may well have different ideas of what constitutes a good quality

service. Byers (2005) cites Barnes and Wistow (1992) as saying there are two broad positive purposes for involving service users, which are:

1. a desire to improve the quality of services to make them more sensitive to the needs and preferences of the individuals who use them
2. to develop a strategy to extend the capacity of users to participate in the decisions of the design, management and review of services (Byers, 2005, p. 2).

Warren (2007, p. 25), a non disabled academic suggests different aspects of service improvement as being important to service users and services. For service users, 'involvement provides an opportunity for people to have a say in matters that directly affect their lives' and for service providers it gives the opportunity to provide 'better targeted services' through 'service users and carers bring[ing] their own unique perspective of services and support, which can be used to develop better ways of meeting need' (Warren 2007, p. 26). Barnes and Cotterell (2012) cite examples of participation in social work and health practice and highlight that practice which takes account of service users' views is seen as 'good practice'. However, they identify power differentials and inconsistencies which compromise this aim (Barnes and Cotterell, 2012 p. 74). Beresford (2012) suggests a different way of understanding the motivation of service users and states that they are more interested in improving people's lives rather 'than just trying to improve services that may impact on them' (Beresford, 2012, p. 26). He then goes on to say that most service users 'get involved' to "make a difference' and to be able to influence and change existing arrangements' (Beresford, 2012, p. 27). Evans, a disabled social worker and Jones, an academic (2012), writing about the Wiltshire and Swindon Users Network (WSUN), which consists of disabled people and older people, state that the Network:

...sought to have collective influence and impact through their involvement based on the expertise of their "lived experience"... As WSUN negotiated different kinds of involvement in health and social care, what was most valued



were those possibilities where greatest immediate impact could be achieved (Evans and Jones, 2012, p. 89).

Making services accountable for the organisation's decisions is an aspect highlighted by Barnes and Cotterell (2012) who state that the 'promotion of user involvement in service decision making is also seen as a means of ensuring accountability and balancing managerial and professional power' (Barnes and Cotterell, 2012, p. 73). All of these joint motivations are concerned with the influence of spaces outside of the participatory space.

**b) From a service user perspective**

The literature often explores the realised 'gains' rather than the motivations of service users. The development of skills is cited by some. Changing Our Lives User and Carers Forum (2008) details an approach to participation which sees service users as leaders and traces the development of leadership skills amongst service users. Warren (2007) lists the provision of 'learning opportunities' as being a potential benefit for service users in relation to an increase in knowledge and skills enhancement as well as education and employment opportunities (Warren, 2007, p. 26). The research cited by Warren to substantiate this claim was specifically in relation to young people. These 'benefits' are concerned with how service users learn from professionals and through the process of participation can take these new found skills outside of the space to apply elsewhere. Writers are not as forthcoming in relation to what new skills professionals have learnt and how their practice is affected by the process. It also does not specifically address how the skills of working together are used in the participatory space.

Other literature cites solidarity with other service users as a gain from being involved in participation (Byers, 2005). This can include gaining an understanding of their own experience and a more positive outlook as happened with the participants with mental health needs in the Changing Minds programme (McKinley and Yiannoullou, 2012).

Byers (2005) also identifies personal gains for service users such as the sense of unity and the way their identification with each other gives them a stronger voice. The literature does warn about the possibility of 'colonisation', however, with the service user voice being weakened as Gosling, a service user representative writes:

Incorporation, colonisation, commodification-lots of reasons *not* to get involved as partners. And yes this is precisely why we *must* continue to involve ourselves. We need to reclaim the purity of our early values, ideals and concepts and we need to challenge the diluting and compromising of them within present partnership poor practice (Gosling and Martin, 2012, p. 15).

Barnes (2012) also refers to 'colonisation' and applies it to a disability organisation being colonised by non-disabled experts. Rather than be colonised, service users can seek to 'turn the tables' and if not colonise in turn then at least to influence, trying to ensure that their values are integrated into services or policies (Barnes, 2012, p. 174). This really does draw attention to the relationships within the participatory space and the role of power. The question 'whose space is it?' is suggested.

A contrasting view is discussed by Hodge (2005) who writes of some service users from the mental health system seeing participation as a chance to distance themselves from the service user identity as it gave them the opportunity to be associated with professionals. However, talking of an interview with a service user Hodge comments,

The problem that the extract does highlight...is the way in which user involvement initiatives like the forum can serve to objectify the personal experience of service users, in the process reinforcing what for many is experienced as an imposed and negative identity of 'service user' (Hodge, 2005, p. 173).

It seems that irrespective of the wishes of service users to be associated with each other or with professionals, the outcome is the same for them-they are seen primarily by professionals as service users rather than as co-participants in the process and therefore different.

A sense of identity and solidarity amongst disabled people and the resulting political motivation for participation is discussed by Beresford and Branfield (2012). They trace how issues of identity have been key issues for social and political action and indeed how identity has been central to many movements, for example, women's and black civil rights (Beresford and Branfield, 2012, p. 34). They describe how movements of disabled people exerted political influence from outside political parties. This proved to be more effective than trying to exert influence from within political parties. Oppression was recognised as existing within political parties and this was a barrier preventing disabled people from being able to exert influence. This has in turn given rise to an enthusiasm for what the authors call 'participatory' or 'direct' democracy in which:

people can be actively involved, campaigning and working for local and global issues that concern them both because of their particular standpoints resulting from who they are and their broader collective sense of social responsibility for their society and the planet (Beresford and Branfield, 2012, p. 35).

If this is seen as the context for understanding service user involvement then this gives a much broader and perhaps richer aspect to consider. It broadens the purpose beyond the immediate, such as improving the quality of and reviewing services and beyond the scope of gaining individual support from group processes to the wider context of political awareness and action. These motivations again focus on the outcomes of participation as a means to an end rather than on the process itself. The importance of the participatory space is the effect it can potentially have on wider spaces. Barnes and Cotterell (2012) refer to the process of service user participation as

‘an overtly political process with objectives of enabling greater equality and more democratic decision making as well as securing improved services’ (Barnes and Cotterell, 2012 p. 73). There is acknowledgement here that the participatory space can also be seen as a political one, which is an important issue for service users.

**c) From a service provider perspective**

The understanding that service providers gain of the subjective world of service users is cited in the literature as being a motivating factor for participation for them. Warren (2007) discusses ‘potential benefits’ rather than the motivation of service providers in relation to participation. She cites ‘recognition of service users and carers as experts by their experience’ by service providers as one of these benefits. She explains this by stating ‘no one else can have the same experience, the same initial contact with services or the same journey...through the social work or social care system’ (Warren, 2007 p. 26).

Hodge (2005) also notes that one of the purposes of forums such as the mental health forum he describes is to understand the subjective worlds of service users. This is presumably to enable service providers to provide an appropriate service which meets the needs of service users, although this is not actually stated. However, Hodge points out that professionals are not expected to share their subjective worlds. Gosling, writing from a service user perspective gives a totally different perspective and talks of the possibility of involvement being ‘voyeurism’. She states:

When we survivors get asked if we need professional therapists to attend to the wounds and the thorns of our past, this is often a subtle way of blame shifting. By claiming and redefining the story within professional territory, the storyteller is rendered ‘vulnerable’ and impotent, and stories become the ‘problems’ that only experts can untangle, rather than the powerful testimonies of injustice and inhumanity which have inspired bottom-up solutions (Gosling and Martin, 2012, p. 11).

Some authors question the motivation of service providers. Hodge's paper (2005) seems to suggest that although the stated aim of the participation was to improve services, the actual aim of the professionals was to meet the requirements for participation. She also notes that at the same time the real aim of those taking part in the forum was to limit the influence of the service users involved. Carr (2012) discusses Hodge's paper and demonstrates how Barnes builds on it to show how some knowledge is excluded or 'off-limits'. Carr refers to the 'rules of the game', by which she means the way the participatory space is managed. Carr draws on an article where Barnes concludes that these 'rules' are used to exclude 'contested knowledges' as well as to prevent emotional expression (Barnes, 2003). Barnes gives an example of participation involving psychiatric survivors in Canada where the professionals took the view that 'horror stories' were 'outside the remit of the committee' (Barnes, 2002, p. 328). Carr cites a later article by Barnes where she writes:

...public officials find any emotion-whether it be anger, pain or despair, difficult to handle in the context of deliberation directed at issues of policy or service delivery. The onus on managing emotions thus rests with the service users or citizens taking part, officials can invoke institutional rules and norms to define what is acceptable in contexts they control. (quoted in Carr, 2012, p. 41)

Warren (2007) cites other 'potential benefits' for service providers as being the challenge of traditional assumptions, more effective two-way communication and the improvement of relationships between service users and service providers. She highlights an important misunderstanding of participation amongst service providers:

One problem that has been highlighted in the literature is the propensity for agencies to focus on the 'intrinsic benefits' of participation-that is how service users and carers have gained personally from the experiences of participation, rather than on the changes achieved...It is important ...for agencies to respond

to what service users and carers have said during the participation process –as outcomes, impacts on improvements and change, as a result of participation, are the primary purposes of participation (Warren, 2007, p. 26).

What the literature highlights is that a participatory space may be that in name only if the motivation of the organisation is that of ‘ticking a box’ rather than genuinely wanting to participate alongside service users in decision making. It can also be a space in which service users feel that rather than their unique perspective being valued, they are required to share their experiences. These can then be viewed as problems to be solved rather than experiences for professionals and service users to learn from together. A further perspective that a spatial analysis brings to thinking about participation is the role of professionals. It asks questions about their role, their knowledge and about their experience of being in a participatory space. It is difficult to find these issues explored in the literature, thus highlighting the unequal way in which people are treated and considered.

The way in which participation is understood fundamentally influences how it is implemented. The next section will examine ways in which participatory spaces have been experienced by services users.

### **3. How service users experience a participatory space**

#### **a) As a space where service users are prevented from having any influence**

The definition of participation agreed earlier in the chapter highlighted that the purpose of participation is to achieve change. However, the literature cautions that participation rather than being a means of influence by services users can instead be a means of controlling them (Barnes, 2003; Hodge, 2005; Carr, 2012). Byers (2005) has a cautionary word here about communicating clearly and honestly with service users in relation to what can and cannot be changed. Byers comments that training should be given to service users to help with understanding this. Whether this is regarded as providing education or exerting control may be a matter of perspective. Regardless of

the stated aims of participation, studies have indeed shown that the very process of participation can be used as a means of control. Training, I would suggest, is also needed by professionals rather than it being taken for granted that they already have the necessary skills. This need is highlighted in Croft et al (2011) in the context of staff involved in person centred approaches and it seems equitable that the same should be true for professionals involved in participation.

Some service users experience the participatory space, the process and its outcomes as being dominated by professionals. Hodge's study (2005) is based on a participatory space in a forum in which people with mental health needs met with professionals from the provider services to improve mental health services and challenge poor practice. This study gives a very good example of how a participatory space can look like a space where services users are actually listened to, but the reality is very different. The purpose of the forum in Hodge's study was to improve mental health services and challenge bad practice. The participation within the forum did have seemingly positive outcomes as it produced a mental health charter to which all local agencies were asked to sign up. It also acted as a consultative body for new developments in mental health policy. Despite what might on the surface look like an example of participation with positive outcomes, a number of ways of controlling service users is documented by Hodge including resisting the discussion of topics which service users wanted to discuss and using the service user chair to move agenda items along when this suited the professionals.

Hodge concludes that the power dynamics which exist in the wider mental health services are replicated in the forum. This reinforces the earlier point about the importance of what actually happens in a participatory space and comes from a different perspective. Hodge's example shows how services exert influence on the participatory space. The way the discussions were managed by officials in the forum amounted to 'a significant exercise of power' (Hodge, 2005, p. 174). The paper highlights the need for user involvement initiatives to be clear and explicit about their

remit, and particularly about the limits of debate. This kind of participation is far removed from the aspirations of the disability movement as it amounts to a replication of service users' negative experiences within the service. It could be argued that this is worse than having no participation as it appears to be inclusive, but in reality is not. It has outcomes which can be seen such as producing a charter, but if this is the result of professionals controlling the process then it will surely not truly represent service users' views but merely reflect the agenda of officials.

Service user forums are one way in which organisations or services try to create a participatory space. Brandon (2005) discusses the concept of a service forum, saying it is 'a theoretical construct, encapsulating the routines and regimes that officially and unofficially transmit and block power' (Brandon, 2005, p. 325). Brandon discusses participation in a day centre for adults with a learning disability where there was a mismatch between the aims of the forum to include service users, the service culture and individual actions of staff members. Brandon concludes that organisations need clear procedures to counteract the potentially alienating environments in which participation takes place. For Brandon it is important to understand and challenge individual staff members' attitudes to power sharing.

Dow (2008), a service user, writes of his experience of being involved in a participatory space in Scotland with service user and carer consultants and three Universities who worked together on a social work education project funded by the Scottish Institute of Social Work Excellence in Social Work Education. Dow was initially very pleased to be asked what his views were and saw the invitation as an opportunity to trust others, to be valued and considered as a partner. However, he became unsure if anything changed as a result of all the meetings he went to. He felt valued when he was asked to do pieces of work, but not valued when he challenged those in power. 'When challenge comes, lines of power are drawn again. But change can only be achieved if that power is shared' (Dow, 2008, p. 53). Dow cites mutual trust and power as vital in the 'journey' from involvement to influence. He states that everything can be lost if



trust is lost and this can be through one thoughtless act. He feels that those in power need to demonstrate that they want to be part of the journey with service users (Dow, 2008, p. 54). This is control 'by the back door' as power is exercised through what is purported to be an act of participation. Dow's writing is challenging in that it shows the emotional journey of a service user and his growing awareness of the limitations of some participatory spaces. It shows the movement in his own political awareness from a grateful recipient of invitations to a thoughtful challenger of those in power.

Staniszewska et al (2012) discuss the negative experiences of patients' participation in health service planning, development and evaluation. They base their discussion on research undertaken by the National Centre for Involvement between 2006 and 2009 into participation of patients in service and policy development. They provide a word of caution about the possible low reporting and hence perhaps unrepresentative nature of the research. Although there were reports of positive outcomes for patients, there were also reports outlining concerns with how patients were involved. They cite one patient as saying 'A lot of it goes over my head because I'm not familiar with everything they are talking about. I was a patient and I've never heard about this side of things' (Staniszewska et al, 2012 p. 132). Staniszewska et al also cite studies of patient involvement where 'Lay board members rated their influence as fairly limited on key decision-making boards...A small number felt that their skills were underused....In addition, some felt ineffective due to a lack of technical knowledge' (Staniszewska et al, 2012, p. 136).

It seems from the literature discussed above that there are a number of ways to organise a participatory space in a way which actually disempowers service users. However, this is not always the experience of service users as some literature also reports positive experiences in a participatory space for service users.

- b) As a space where service users can feel personal gain, influence services and achieve positive changes**

Although the definition discussed earlier of a participatory space is concerned with the exercise of power and decision making, it is the process by which this happens as well as the outcomes that service users cite as important in making them feel valued. Gosling and Martin (2012) discuss examples of participation with service users and professionals working together where the service users involved in them state how they have benefitted. The service users perceive personal gains as including gaining confidence in what they have to contribute, personal development, more self awareness including reassessment of the past, development of skills, broadening of social network, realisation of the value of passion for a cause, gaining confidence in own judgments, how to challenge others and learning about trusting others (Gosling and Martin, 2012, pp. 197-200). All of these benefits are as a result of the *process* of participation rather than the *outcomes* of the particular project they were working on. In other words, they experienced them in a participatory space.

Staniszewska et al (2012) identifies 'personal gains from new social contacts...feeling valued and listened to...and being personally rewarded' (Staniszewska et al, 2012, p. 131). They also identify the development of new skills such as presentation skills and learning about how to influence large organisations, in this case the NHS. Some of the literature discussed above also talked of skills development, but this was in relation to how they could be applied outside of the participatory space, whereas Staniszewska et al (2012) refer to skill development in the context of the participatory space. What I could not locate were references to how professionals developed their skills in this context or where the learning and skills development was mutually shared by professionals and service users.

Other literature reports that service users have effected change through participation. McKinley and Yiannoullou (2012) discuss the benefits for service users involved in a mental health awareness raising project. They comment on how 'clinical outcomes' have improved for service users 'as people have learnt to work with others, develop new skills and feel heard and valued' (McKinley and Yiannoullou, 2012, p. 117).

They cite one service user as saying: 'I'm proud to be a service user and I wouldn't have said that before this experience' (McKinley and Yiannoullou, 2012, p. 118).

As reflected in the citations above, most of the literature focuses on the personal gains for service users rather than the changes that take place in services or in decisions.

#### **4. Barriers to the development of a participatory space**

It is possible for the individual benefits cited above to be gained and no actual change take place outside of the space. The experience of being in a participatory space may be positive for some service users, but the outcome may be less satisfactory. One reason for this identified in the literature is a reluctance of professionals to share power with service users. Carr (2007) comments on the challenges that participation has presented to organisations, saying it has exposed issues at political, strategic and structural levels. Carr (2004, p. 14) identifies problems in participation concerning power sharing including 'dominant professional perspectives and attitudes towards service user decision making capability.' Carr cites an NHS report which also identifies 'professional power, assumptions about expert knowledge, professional defensiveness and lack of organisational expertise in engaging with service users as impeding the process of change'. Some organisations do not seem to have the political will or the skills which are necessary to make a space participatory. Instead, spaces are being created which might be named participatory, but in fact are just a replication of the power relations which already exist. Service users in these spaces are used to reinforce the status quo. Service users may feel valued as they gain new skills and so forth but a participatory space that leads to change outside of itself results in service users feeling valued about the way they have exercised power (or not valued if no change occurs) (Dow, 2008; Fleming, 2012).

The need for change to result from a participatory space is given voice by Barnes and Cotterell (2012). They discuss 'democratic participation' and conclude that a different way of working is needed as opposed to 'traditional' ways of working. New ways of working can 'threaten the power of providers.' However, it can also 'be a way of

building different types of relationships between service providers and users' (Barnes and Cotterell, 2012, p. 76). Barnes and Cotterell state that unless structural changes take place within organisations which allow participation to take place, 'effective participation is unlikely to be maintained and an effective challenge to people's exclusion and oppression is unlikely to occur' (Barnes and Cotterell, 2012 p. 77). It is clear from the literature that for a space to be truly participatory, power needs to be shared by professionals with service users and that they be empowered to exert influence in decisions. The development of different types of relationships between service users and professionals that Barnes and Cotterell refer to are what are needed for a space to be participatory. Although the purpose of a participatory space is to influence change, it is important to examine what happens in the space itself. If a space is a way of controlling, rather than empowering service users, then it will not be able to influence any changes that reflect the values or wishes of service users. The way relationships are conducted and power shared is highlighted in the literature about participatory research and it is to that which I now turn.

## **Part 2, Participatory research**

(Since the completion of the research, studies have been published of research with people with autism and Asperger's syndrome. Rather than consider these as part of the Literature Review, I will consider them in the methodology chapter as they did not inform the design of this research as they were not available then.)

Participation should not be an end in itself but should be a means to an end, a means of achieving change (Carr, 2012). The emphasis in the literature discussed in part one of this chapter has been concerned with the experiences of service users in participation and how agencies either enable or prevent change taking place through what is purported to be participation. The discussion so far has not taken into account the role of service users in participation and this part will address that by exploring the literature in relation to participatory research. One debate in the literature which draws attention to the perspective of service users is that of the difference between

participatory and emancipatory research. I will discuss what the literature says about this debate and discuss how an emancipatory research space might look different from a participatory research space. I will discuss a third type of space, a co-created research space and examine what that might look like, based on the literature. The literature often refers to disabled people and non disabled researchers taking part in research and I shall refer to the same where authors have done so. However, the principles should also apply to any group of participants such as young people. Much of the debate about co-researchers is concerned with disabled people and where this is the case, I will also refer to disabled people rather than co-researchers generally.

### **1. Participatory and emancipatory research spaces**

I will explore what the literature says about participatory and emancipatory research and relate this to the concept of metaphorical research spaces. I will firstly explore 'participatory research spaces' and secondly, 'emancipatory research spaces'.

#### **a) What is a participatory research space?**

Some of the authors who write about participatory research do so in quite negative terms (Zarb, 1992; Oliver, 1992). The reason for this is that it is criticised as an approach where power is not always shared. As discussed above in relation to participation in service or policy development, there are examples where power is shared and examples of where it is not. This is also the case with participatory research. There are however good examples of participatory research where care has been taken to ensure that co-researchers were able to contribute to every part of the research process so that power was shared. Two positive examples amongst many are in relation to the LGBT community (Browne, Bakshi and Lim, 2012) and service users in the Standards We Expect Project (Fleming, 2012).

Participatory research has a political dimension (Bradbury and Reason, 2006) and in turn, a research space also has a political dimension in that its purpose is to address practical problems in the community and shift the balance of power in favour of

marginalised groups (Reason and Bradbury, 2006). As Reason and Bradbury state: 'The political imperative is not just a matter of researchers being considerate about their subjects or acting ethically: it is about the democratic foundations of inquiry and of society' (Reason and Bradbury, 2006, p. 10). The criticism of this is that the power is still left with researchers and power is only shared at their discretion. Oliver writes:

The problem with all of these (participatory strategies-my parenthesis) is that they do not confront the objective structures of oppression and despite personal intentions in many cases, disabled people are still positioned in oppressive ways. Whether we like it or not, failing to give disabled people, through their own representative organisations, complete control over research resources and agendas inevitably positions disabled people as inferior to those who are in control (Oliver, 2009, p. 110).

The criticisms of participatory research relate to the retention of control by non-disabled participants, including who should be involved and how (Zarb, 1992). It is also criticised for utilising the knowledge of professionals (Zarb, 1992) and 'packaging' the 'voice' of disabled people in a way that reflects what 'experts' say (Walmsley and Johnson, 1998). Partnerships tend to be between individuals rather than based in the context of organisations (Chappell, 2000). Some of the literature even conceives of a participatory space as a 'failed' emancipatory space where researchers were unable to reach the goals of emancipatory research (Chappell, 2000). However, the same writer acknowledges that participatory research usually takes place in the context of a committed and sympathetic researcher who is trying to conduct research together with disabled people, rather than on their behalf (Chappell, 2000).

Oliver's and others' criticisms as cited above do not allow for the possibility that participatory research can avoid replicating the inequalities in society, which is the intention of many researchers as acknowledged by Chappell (2000). However, Beresford (2005) does allow for the possibility of 'user involvement' in research to

achieve this, although he acknowledges that much of what he refers to as 'user involvement' does mirror rather than challenge 'exclusions and discriminations'. Beresford proposes that there are two 'key and related lessons' that need to be put into place in order for user involvement in research to 'work for *everyone*' and they are *access* and *support* (Beresford, 2005, pp. 9-10).

A participatory space then is one where power is shared and co-researchers are enabled to work in partnership with the researcher as access and support are adequate. By access, Beresford means that there are 'structured, ongoing ways of being involved; of engaging with services and agencies, of getting in and connecting with structures of organisation, management, control and decision making' (Beresford, 2005, p. 10). By support, Beresford means: 'people can expect to have whatever help, support, encouragement, information and skill development they may each need to contribute what they want to, how they want to' (Beresford, 2005, p. 10).

The difficulties that can arise when researchers retain control over the research is highlighted by Kindon et al (2007), social geography academics who list the following as 'some negative power effects of participatory approaches':

- Retention of researcher's control whilst presenting them as benign arbitrators of neutral or benevolent processes
- Re-authorisation of researchers as experts *in* participatory processes
- Reinforcement of pre-existing power hierarchies among participating communities (Kindon et al, 2007, p. 21).

This shows the potential for participatory research to replicate the power relationships which are experienced in society with co-researchers being denied power by researchers. It does seem that one similarity between participatory research and participation as discussed earlier in this chapter is the role played by professionals/researchers and their skills and willingness in working with co-researchers to provide a facilitative process where power is shared. Due to the potential for participatory research to be experienced by co-researchers as a denial of

power to them, emancipatory research was proposed as an alternative by Oliver (1992) and Zarb (1992). Emancipatory research is where service users control the research rather than have power shared with them. For disabled academics such as Oliver, this is the only type of research that does not mirror the inequalities in society.

**b) What is an emancipatory research space?**

Zarb's seminal paper (1992) began the discussion on the differences between participatory and emancipatory research. He outlines two primary principles for emancipatory research of 'empowerment' and 'reciprocity' as distinguishing features. Oliver (1992), referring to the work of Gollop adds a third primary principle for emancipatory research of 'gain' for the disabled co-researchers (Oliver, 1992, p. 111). An emancipatory space utilises the knowledge that is grounded in the circumstances of everyday life and is 'illuminated' by the struggles of co-researchers (Oliver, 1992, p. 111). It is a space in which the researcher as well as co-researchers can come to understand themselves better, and hence be changed (Oliver, 1992, p. 112). An emancipatory space is somewhere where co-researchers can empower themselves. This empowerment should come from the co-researchers themselves, rather than from the researcher (Oliver, 1992, p. 111). The space provides the context in which empowerment can take place through the facilitation of the research process (Oliver, 1992, p 111.). Walmsley and Johnson use different terminology and write about 'inclusive research', but what they refer to fits well with emancipatory research. They pose three questions to determine whether research is inclusive or not: Firstly, who frames the research and how? Secondly, what relationship is established between the researcher and the 'respondent'? Thirdly, who analyses the data and how? (Walmsley and Johnson, 1998). These questions could also be asked of participatory research as a test to see how power is shared. However, in emancipatory research, co-researchers should be 'in charge' of the whole research process and this is usually achieved through democratic organisations of disabled people (Chappell, 2000). In an interesting difference in the literature noted above, Chappell highlights 'intentions' and 'design' rather than outcomes as being defining elements of



emancipatory research. She states that emancipatory research 'strives to achieve the transformation of what Oliver (1992) termed the social relations of research production' (Chappell, 2000, p. 39). This is achieved by an emancipatory space being built on the principles of the social model of disability as a way of understanding disability and improving the lives of disabled people (Chappell, 2000). Some literature indicates that an emancipatory space is one which is only inhabited by service users. As Staddon states about her research:

The project was perceived as emancipatory, in that its Advisory Group was made up entirely of service users, who designed the work, discussed its outcomes at all stages, were able to criticise and comment on the final report, and were active in setting up and running the survivors group at the end (Staddon, 2012, p. 192).

Issues of control and power are highlighted in the literature in discussions of the differences between participatory and emancipatory research spaces. Barnes (2003), a disabled writer, wrote a paper entitled 'What a Difference a Decade Makes: Reflections on doing 'emancipatory' disability research'. The title is interesting in itself as it includes disabled people rather than other categories of co-researchers. In the article, Barnes (2003, p. 7) seeks to define emancipatory research by 'the problem of accountability, the role of the social model of disability, the choice of methods, and empowerment, dissemination and outcomes'. One of the important contributions that Barnes adds to the debate about emancipatory research is in relation to the role of the non-disabled researcher, as will be discussed further below. Barnes writes of the possibility of a non-disabled researcher being involved in emancipatory research when he says: 'Emancipatory disability research is not about biology it is about commitment and researchers putting their knowledge and skills at the disposal of disabled people and their organisations; they do not necessarily have to have an impairment to do this' (Barnes, 2004, p. 8).

## **2. A closer look at emancipatory research**

I am going to explore the different elements of emancipatory research under the following themes as these capture the main areas of discussion in the literature:

- Social model of disability
- Control
- Knowledge
- Empowerment
- Reciprocity and gain
- Transformation

### **a) Social model of disability**

Emancipatory research should be built on the principles of the social model of disability (Chappell, 2000; Barnes, 2003). Barnes considers the importance of the social model of disability to be that it focuses on the 'economic, environmental and cultural barriers encountered by people viewed by others as having some form of impairment' (Barnes, 2003, p. 9). He also states that the social model of disability does not ignore questions of impairment nor does it ignore the relevance of medical and therapeutic treatments (Barnes, 2003, p. 9). According to Barnes, the importance of the social model of disability for emancipatory research is that discussions of disabled people's experiences are framed within the context of a disabling society (Barnes, 2003, p. 10). This is an important point which could also be applied to participatory research. It allows for the possibility of a non-disabled researcher understanding the social model of disability and using this and their experience of being part of a disabling society to contribute to the shared knowledge within the group.

### **b) Emancipatory research and control**

Control by co-researchers over what happens in an emancipatory research space is referred to repeatedly in the literature. Control over all aspects of the research is

important including control over the research process, over the researcher and over how the research is produced:

**i) Control over the research process**

Chappell (2000) cites Oliver's explanation of the social relations of research production, as being a:

firm distinction between the researcher and the researched...the belief that it is the researchers who have specialist knowledge and skills; and that it is they who should decide what topics should be researched and be in control of the whole process of research production (Chappell, 2000, p. 39).

It is this belief that results in the researcher controlling the processes and results in the failure of a research space to be emancipatory. However, according to Koch and Kralik (2006, p. 23), there is a partnership between the researcher and what they term 'research participants' in participatory research and such participation involves these participants in all stages of the research process.

**ii) Control over the researcher**

According to the literature, in an emancipatory space, it is the co-researchers who have control and this includes how the researcher should be involved. This is implied by Oliver (1990): 'In an emancipatory space, researchers have to learn how to put their knowledge and skills at the disposal of their research subjects, *for them to use in whatever way they choose*' (Oliver 1990, p. 14). Oliver's terms 'research subjects' equates to co-researchers in this chapter. This is not a partnership in which researcher and co-researcher mutually decide how to work together, but a space in which the co-researchers utilise the researcher as a resource to meet their agenda.

According to Barnes (2003) the 'salient point' about emancipatory research is that of 'ownership'. As he states, 'Within an emancipatory framework it is organisations controlled and run by disabled people that devise and control the research agenda

and, equally important, to whom and how the research findings should be disseminated' (Barnes, 2003, p. 13).

### **iii) Control over how research is produced**

Walmsley and Johnson (1998) discuss the publication in the UK of *Know Me As I Am: An Anthology of Prose, Poetry and Art by People With Learning Difficulties* (Atkinson and Williams (eds.), 1990). Whilst this publication showed the potential for people with a learning disability to be included in research, the authors note how the production of the book was controlled by the academics. The adults with a learning disability who were the contributors to the book were presented with five choices for the title and chose one, but were over ruled. Walmsley and Johnson identify that the academic researchers were influenced by 'normalisation/social role valorisation, the rights movement and the movement towards qualitative research' and so they wanted what they thought was a more appropriate title to reflect that agenda (Walmsley and Johnson, 1998, p. 78). The end product claims 'Above all, this book gives a voice to a group of people who, historically and today, have often been shut away, avoided and ignored' (Atkinson and Williams (eds.), 1990, back cover). Although there is the appearance of giving people a voice, that voice is 'packaged' in such a way that reflects what the experts think is the most appropriate way to represent people in the context of a political movement.

### **iv) Knowledge**

In a section entitled 'Objectivity-but whose?' Zarb (1992) asks a question about what counts as knowledge and discusses some of his own research with men who have experienced spinal injury. He makes the point that although the research did use experiential and biographical accounts, 'At no point, however, did we consider consulting them about how we should actually carry out the work'. He states that:

Consequently, the way the issues raised by disabled people were investigated and the conceptual framework used for analysing and presenting the data were essentially our own arbitrary constructs and despite our quite extensive

consultation-there was a very marginal input from disabled people themselves (Zarb, 1992, p. 131).

Oliver (1992, p. 107) highlights the need for a new research paradigm for social research which he says has been called 'critical enquiry, praxis or emancipatory research'. According to Oliver, this should have a different view of knowledge and he cites Lather as stating that the knowledge or theory must:

... illuminate the lived experiences of progressive social groups; it must also be illuminated by their struggles. Theory adequate to the task of changing the world must be open-ended, non dogmatic, informing, and grounded in the circumstances of everyday life (Lather, 1987, p. 262).

The difficulty with utilising knowledge that is based on the struggles of co-researchers alone is highlighted by Smith, Monaghan, and Broad, (2002) in a discussion about the validity and reliability of participatory research: 'For some participatory researchers, the question of validity goes right to the heart of the issue as what counts as knowledge' (Smith, Monaghan, and Broad, 2002, p. 197). Smith, Managhan and Broad quote Warren (2000) who argues that conventional assumptions that separate 'research process' and 'the reality we research' are guilty of incorporating dominant and partial ideologies'. This in turn, Warren suggests, leaves open to question the claims to validity that are based on the 'outsider' relationship between the researcher and those being researched. Warren argues instead that the participatory researcher, in being able to bring together 'insider' insights with 'objective' reflection 'generates a fuller understanding of the research subject' (Smith, Managhan and Broad, 2000 pp. 197-198). How possible it is to have what Warren called 'objective' reflection is open to debate and there is always the danger of interpreting knowledge in a way which reflects the researcher's rather than co-researchers' views. What would seem to be ideal is utilising the knowledge of the researcher and the co-researchers:

The important principle here is to seek to bring skills, knowledge and personal experience together in a complementary fashion, rather than to deny the skills or the qualities and abilities of either the professional researcher, or the young people recruited to the initiative (Smith, Monaghan and Broad, 2000, p. 198).

Beresford (2005, p. 15) questions the assumption that professionals are more impartial than service users:

Who is best placed to interpret the experience and knowledge of service users? Is it service users themselves or is it professionals and researchers who can claim to have distance from them and their experience? But then won't the latter often themselves be subject to and socialised into the values and understandings of the service system and therefore liable to be biased because of this?

It seems that what is important is that both researchers and co-researchers are aware that their thinking has been shaped by their experiences, be this on a personal or a professional basis. Not only is reflexivity called for on the part of the researcher, but an honest dialogue between research partners.

In order for the knowledge of the researcher and the co-researchers to be seen as complementary, 'the social relations of research' need to be addressed as these are based on assumptions that 'it is the researchers who have the specialist knowledge and skills; and that it is they who decide what topics should be researched and be in control of the whole process of research production' (Oliver, 1990, p. 102). Koch and Kralik (2006) state that participatory research is where 'ways of knowing are valued...as theory is generated from the experiences, lives and understandings of all participants' (Koch and Kralin, 2006, p. 23). They write of the role of theorizing from experience being used to expose 'false ideologies', stating that this theorising can lead to changes in the lives of those participating as well as being socially transforming.

## **v) Empowerment**

As empowerment is one of Zarb and Oliver's 'primary principles' for emancipatory research, it is evident that they do not consider that empowerment can take place in the context of participatory research, although the two are not necessarily mutually exclusive. The reason for Zarb and Oliver's contention is the view that people cannot be empowered, they have to empower themselves. Empowerment is linked to knowledge in the form of 'self-understanding' and it is this knowledge which can inform both the process and the outcomes of the research. As Oliver states:

Empowerment through self-understanding is a process through which many oppressed groups are beginning to pass and emancipatory research can have a role to play in this. Such self-understanding is an essential pre-requisite to providing a redefinition of 'the real nature of the problem' (Oliver 1990, p. 112).

Barnes (2003), writing more than a decade later, does allow for a non-disabled researcher to be involved in emancipatory research. He writes that emancipatory research is concerned with the empowerment of disabled people 'through the transformation of the material and social relations of research production' (Barnes, 2003, p. 5). He links emancipatory research with the social model of disability as they are linked by their 'transformative aim: namely, barrier removal and the promotion of disabled people's individual and collective empowerment' (Barnes, 2003, p. 5). The researcher's role 'is to help facilitate these goals through the research process' (Barnes, 2003, p. 5). However, Koch and Kralik (2006), two non-disabled academics have a different view of empowerment and participatory research:

There is a focus on empowerment and power relations in participatory research. People's awareness of their own capabilities and capacity is strengthened by their participation in the research process. Empowerment is incorporated in the process of the research by identifying the potential for the imbalance of power in the research relationship and seeking to take action to address the inequity (Koch and Kralin, 2006, p. 23).

An emancipatory space, in this view can provide a context in which co-researchers empower themselves but a participatory space cannot as the 'social relations of research' are such that it is the researcher who controls the process. However, this does not allow for the possibility of participatory research providing a context in which co-researchers can empower themselves as it assumes again that a participatory space will mirror oppressions in society.

#### **vi) Reciprocity and gain**

Reciprocity can be taken to mean 'mutual advantage' and this is the second 'primary principle' of emancipatory research, according to Zarb (1992). During a discussion of this, Oliver (1992) comments that researchers do not tend to reveal as much about themselves as they expect disabled people to reveal to them. This is a different interpretation of reciprocity and a potentially difficult one for researchers to achieve. As we have seen, knowledge is viewed in the literature as being based on the struggles of disabled people which they have to share in the research process. For this to be reciprocated, researchers could share their experiences of oppression, but this could seem patronising to the co-researchers. The purpose of this is difficult to determine beyond making the situation feel more equal. The knowledge that the researcher could bring to the process is how they, as part of society, relate to the co-researchers and this could inform the process of the research as well as the outcomes. It is an understanding of the context in which the 'struggles' have taken place.



Although not specifically referring to reciprocity, Fleming (2010, p. 209) discusses the view that researchers just extract information from co-researchers. In discussing the involvement of young people in research, Fleming cites Petrie who talks of 'extractive research' that 'mines' young people for information. Fleming cites Petrie's alternative view of research where researchers not only try to take information from people but establish relationships with them and give something back, 'with a view to achieving positive change'. Fleming talks about researchers that work with young people being 'builders' and not 'borrowers'. She gives four reasons:

First, involving young people challenges academics on the purpose of their research. Second, it questions the principles behind the research, asking in whose interests is it being done and encouraging the creation of emancipatory research paradigms, with the power considerations that inevitably come from that perspective. Third, and linked, they encourage us to think about how research can provoke change for children and young people. Fourth, it questions the rigour of the research process by identifying from the outset the requirement to understand the context of the area of enquiry that young people as 'experts by experience' are likely to be central to that (Fleming, 2010, pp. 210-211).

Based on this, reciprocity is to do with challenge to the researcher and gain for the co-researchers rather than a mutual sharing of personal information. Gain is the third 'primary principle' that Oliver adds to the original two of Zarb for emancipatory research and so again, the implication is that there is not reciprocity or gain for co-researchers in participatory research. Oliver criticises researchers who work with disabled people to get an account of their experience, produce that account and then move on to something else, leaving the disabled person in exactly the same social situation as they were prior to the research (Oliver, 1992, p. 108). The outcome of the research for the co-researchers is important as, in order for research to be emancipatory, their situation should be improved as a result. How this is achieved or

measured is an interesting question but the principle is that research should not only benefit the researcher, there should be benefits also for the co-researchers.

#### **vii) Transformation**

As we have already seen, emancipatory research is where the social relations of research production are changed and there should also be transformation in the researcher and co-researchers, where 'the researcher and researched become changers and changed' (Oliver, 1992, p. 107). Oliver writes that the methodology must also change and be built on trust and respect: 'Finally, of course, the methodology of research must also change building upon trust and respect and building in participation and reciprocity' (Oliver, 1992, p.107). This trust and respect come with the transformation of the researcher in emancipatory research from that of a 'sympathetically into something more akin to expert advisor' (Walmsley and Johnson, 1998, p.51). The aim of participatory research, according to Koch and Kralin (2006) is to affect the lives of those who participate as well as effecting social change, although they state that the change may begin and end with affecting the lives of participants only. Nind (2014, p. 5) discusses participatory research and states: 'participatory research has an element of doing things in a more participatory way for a reason-to bring about change'.

The key difference between participatory research and emancipatory is that of ownership and control (Barnes, 2003) as it seems that the other conditions could be met in participatory research if it is also based on the social model of disability. What they have in common is the importance of using research to achieve change. The issue of control has been addressed in what has recently been termed 'co-produced research'.

### **3. Co-produced research**

In recent years, a new term has emerged for research; that of 'co-produced' research and this is a term which I have used throughout this chapter. This has been developed

to address the debates about control and is concerned with a process which is jointly controlled. The term 'co-production' applies to projects where service users and the professional workers from the services that they receive work together. It 'refers to active input by the people who use services, as well as – or instead of – those who have traditionally provided them' (SCIE, 2009, no pagination).

Co-production recognises that service users have assets, such as expertise, skills and mutual support which can contribute to 'effective public services' (SCIE, 2009, no pagination). According to the SCIE report: 'Co-production is a potentially transformative way of thinking about power, partnerships, risks and outcomes' (SCIE, 2009, no pagination). Crucially, the report also states: 'To act as partners, both users and providers must be empowered. Co-production means involving citizens in collaborative relationships with more empowered frontline staff who are able and confident to share power and accept user expertise' (SCIE, 2009, no pagination). Discussion of the nature of participatory and emancipatory research has led to a refinement of the concepts which have grown in sophistication to address the criticism as outlined above. The debates led to the differentiation of participatory and emancipatory research. Control of the process, knowledge, outcomes, the relationship between the researcher and the co-researchers and whether the process facilitated empowerment or not are the deciding factors regarding how the research is categorised. Co-production is a way of conducting research which sees these aspects as shared, rather than controlled by the researcher or the co-researchers. Although this is a fairly recent term at the time of writing, the practice is not necessarily new with some research that was previously labelled 'participatory' achieving the same level of partnership between co-researchers and researcher as the term 'co-production' indicates. What the term does is to define more tightly the relationship between the researcher and co-researchers.

Throughout this chapter, I have used 'co-produced' when referring to research and 'co-created' when referring to a research space. Extending the principles from Durose et al

(2012. P. 6) in relation to co-production to the co-creation of a research space, we can conclude the following:

1. In a co-created research space 'interactive knowledge' is developed which rests on developing a 'shared thought style'.
2. This would work by creating a 'boundary space' which would facilitate the world of the researcher and the world of the co-researchers.

According to Durose et al:

Such spaces may require facilitation capable of enhancing communicative processes, making different thought styles visible and linking them around common interests; promoting joint reflection towards a common understanding of situations and collective action; as part of a learning process based on respect, openness and deliberation.

Oliver's point about reciprocity being concerned with mutual sharing is addressed in such a space: 'A key barrier to co-production is where academics see themselves as not representative except of themselves and their own work. An important building block towards co-production then, is the researcher's reflexivity' (Durose et al, 2012 p. 8). As suggested above, the researcher does not necessarily share personal experience, unless this is appropriate. Instead, the researcher contributes with their understanding of the social context, their role in that and how this relates to the experiences of the co-researchers.

Recent literature has discussed co-produced research and the elements of this include developing 'non-hierarchical approaches to integrating the perspectives of different team members into the analysis process' (Gillard and Turner, 2010, no pagination). It allows for the questioning of the assumptions of the researcher in terms of the significance of findings. It also allows for service users' views of the significance of findings to be utilised (Gillard and Turner, 2010, no pagination). In a paper delivered two years later on the same research, Gillard et al (2012) state that the different views

of researchers and co-researchers in their research revealed the complexity of relationships between academics and service users. They conclude that co-production should include the exploration of the different voices of the service users and academics and what these mean in relation to each other (Gillard et al, 2012). Interestingly, Gillard and Turner use a spatial metaphor to explain how they had moved to co-produced research: 'we felt that we had moved beyond making spaces for service user and carer involvement in our team, and had successfully begun to 'co-produce' our research...' (Gillard and Turner, 2010, no pagination).

A series of questions framed by Turner (2012, no pagination) were designed to investigate the impact of co-produced research on the researcher as well as co-researchers:

- How are decision-making roles distributed across the research team?
- How does who we are shape the knowledge we produce?
- How even is the co-production of knowledge throughout the life of the project?
- Are/what steps are taken to even up the co-production of knowledge?
- How does the research team reflect on the research process?
- How is the co-production of knowledge disseminated?

The issues addressed in these questions are the same as some of those discussed above in relation to participatory and emancipatory research in that they are concerned with decision making and knowledge production.

Issues of power will always need to be addressed for any co-created space to be true to its name. This can only be achieved by considering the issues raised in the discussions above regarding participation as well as participatory and emancipatory spaces. A co-created space could become another type of space over time with more powerful professionals exerting control and limiting influence. A co-created space would have to be a space in which the questions suggested by Turner (above) need to

be continually reviewed. Haywood (2000) gives an account of how the 'powerful' can behave in research:

They use power... interfering with choices that the powerless would make, but for power's exercise. The powerful coerce the powerless. They manipulate them in ways that change their conduct. They teach them to anticipate defeat, and therefore not to challenge the status quo. At times, they even induce the powerless to misapprehend their own preferences and to act in ways contrary to their interests (Haywood, 2000, p. 2).

The challenge of a co-created research space is for researchers and co-researchers to address their own roles in the space together. Service users as co-researchers need to empower themselves as Oliver maintains for emancipatory research but in the context of mutual learning and reflection. Researchers and co researchers need to engage in reflexivity and both need to acknowledge the influence each has on the other (Durose et al, 2012). These reflections were all relevant to participatory research but in the reframing of participatory research as co-produced research, the challenges are made more explicit.

Nind (2014, p. 6), when discussing whether participatory research is a research method or a research paradigm cites Cook who also uses a spatial metaphor. Cook states that participatory research 'inhabits different spaces and offers different ways of seeing'. Nind (2014, p. 7) also cites Thomson who regards participatory research as 'spatial practice'. Nind (2014, p. 7) writes: 'Spaces for life experiences to be discussed may be 'closed' (or 'invited') spaces, directed by the researcher, or 'claimed/created space' in which participants can create new power and possibilities'.

This idea of a metaphorical space where new possibilities can develop is also explored in the work of Bolzan and Gale (2011). They developed the idea of an 'interrupted

space' as a research space which can be empowering to the co-researchers and allow for new possibilities.

#### **4. Interrupted space**

Bolzan and Gale (2011, p. 505) have coined the term 'interrupted space' when discussing their own research with young people. An interrupted space 'provides the opportunity for social actors to experience something different, something outside of their usual daily routine, and make meaning of it'. They used this approach to create a space where young people could explore 'new ways of being' and have their insights valued by adults. Part of creating this space was to give the young people as many choices as possible, within the constraints of the funding committee and recognising the power difference which exists between adults and young people (Bolzan and Gale, 2011, p. 506). The young people were able to choose what activities they did and take part in them together. For the young people, social life became different and no longer predictable when they occupied the interrupted space. The young people were able to assign meanings to activities which adults could not have predicted (Bolzan and Gale, 2011, p. 508). The young people were given the opportunity to make decisions in the interrupted space, an experience that was usually denied them with the possibility of an adult to help if they chose. As Bolzan and Gale (2011) write, 'This space afforded the young people the opportunity to exercise agency in a resourced environment' (Bolzan and Gale, 2011, p. 513). Bolzan and Gale reflect that one of the important features of the space is that it was 'safe if they were to take chances and exercise agency' (Bolzan and Gale, 2011, p. 513). The young people also needed to feel respected and that their contribution was valued.

#### **5. Implications for my research**

In the previous three chapters, I have discussed situations where disabled people were literally sent to separate physical spaces; how this experience gave rise to a new awareness amongst disabled people and they fought for their own metaphorical spaces within the disability movement as well as how these can be compromised by being absorbed by organisations for but not run by disabled people. I discussed what

an autistic space might look like and how autistic people have to live within the more dominant neuro-typical spaces.

These debates, together with those outlined in this chapter informed the way I conducted my research. In forming a research group, I needed co-researchers with whom to co-create a research space which was also an autistic space. This space should be one in which the co-researchers were able to empower themselves, facilitated by the co-creation of our research space. I wanted to be aware of my own role in the production of the research process as well as in the dissemination of knowledge. I wanted to develop a relationship in which both I and the co-researchers might change and learn from each other. I recognised that these considerations constituted a research issue and my reading confirmed this. From the writing about interrupted space I saw the possibility of co-creating a space in which the co-researchers could express their agency and be free from the limitations of a space dominated by neuro-typical people-a space in which they could be free to reflect with me rather than just by using my assistance as in a participatory space.

From the discussion in Chapter Two about autistic spaces, and the discussions above about research spaces, these are the characteristics which I hoped our co-created autistic space would have:

- The underpinning philosophy is that of the social model of disability, recognising that the co-researchers will have experienced oppression and disabling barriers
- The researcher will have a commitment to not replicate disabling barriers, but seek to work with the co-researchers to find ways to remove these
- Power is shared, within the constraints of ethical approval
- Control of the process does remain with the researcher, but every effort is made to make and share all decisions with the co-researchers
- The researcher and the co-researchers work together on and agree the research design, data collection, data analysis and the dissemination of results



- The co-researchers are given the opportunity to co-create a space in which they feel safe or comfortable and which operates in a way which is natural to them rather than is comfortable to the researcher
- The researcher will have a commitment to finding what these ways of working are together with the co-researchers
- The researcher and co-researchers will be reflective and consider new ways of thinking
- Every effort will be made to represent the research findings in a positive way and to the benefit of other people with Asperger's syndrome or autism
- There would be mutual gain by the co-researchers and the researcher

My methodology was informed by this theoretical understanding of what a co-created autistic research space should look like. In the next chapter I turn to a presentation and discussion of my research methods based on this.

## **Chapter Five**

### **Methodology I**

#### **Important context in relation to the data set**

This and the following chapter will consider the methodology used in this research. It is important to note at the outset the nature of the data set. One of the unusual features of this research is that strategic project development, data collection, analysis and dissemination all form the data set. The data consists of the following, all of which are incorporated in the discussion below:

- Responses to the questionnaire
- Notes from group discussions between myself and the co-researchers from their records of the meetings and my reflective log
- Interviews and focus groups
- Group discussion between myself and the co-researchers and analysis of new data arising from focus groups and interviews
- The Conference: this served as dissemination of what the research found and created new data from the scripts for the conference and the feedback from attendees.

As the fit of these elements is quite complicated, a guide to the structure of this and the following two chapters will aid the reader.

#### **Chapter Five**

1. Context in which the research took place



2. Co-creation of an enabling research space



3. The questionnaire



#### **Chapter Six**

4. Focus groups and individual interviews



5. The conference as a means of dissemination and data production



6. The value of this research



7. Revisiting the research aims

*Figure 1: Structure of Chapters 5 and 6*

This chapter will focus on the first three elements of the methodological consideration and the next chapter will consider the last four.

A timeline of the activities which produced the data will be provided later in this chapter prior to the data being considered. Before this, I will consider the context in which the research took place, including the aims, assumptions about myself and the co-researchers and knowledge generation.

## **1. Context of the research**

### **a) The research aims**

As stated in the Introduction, the impetus for this research came from my personal experience and professional background. I wanted to explore my research question of 'What support do adults with Asperger's syndrome want?' I also wanted to conduct participatory research with adults with Asperger's syndrome as I was unaware of any examples of this at the time of commencing the research. From the Literature Review, my understanding of how people who are considered disabled are excluded from society was strengthened, as was my understanding of the disability movement and disabled people's struggles to gain influence over the services that they receive. It also

strengthened my understanding of how people with Asperger's syndrome are perceived. Foucault's work helped me understand the link between knowledge and power which I applied to the discourses relating to Asperger's syndrome.

The literature on participation and participatory research highlighted issues of power and control and I became much more aware of the ways in which control is exerted over disabled people and people who take part in research. Through my reading, I identified a gap in the literature at the commencement of this research in relation to participatory or co-produced research with adults with Asperger's syndrome as well as a lack of any discussion of this group in relation to the social model of disability. (As eluded to in Chapter Four, since completing the research, I have read of recent participatory studies involving adults with adults with Asperger's syndrome (MacLeod et al, 2013) and I will discuss these studies later in this chapter). My aim was to co-create a research space with adults with Asperger's syndrome and put into practice the learning from my reading in relation to participatory research, the social model of disability and the ways autistic people might prefer to communicate. In addition, I wanted to explore whether people with Asperger's syndrome would be able to be co-researchers, although my personal conviction was that they could, if the research was conducted in an enabling way. I also wanted to explore what a wider group of adults with Asperger's syndrome thought about the support they needed. I wanted to see how the co-researchers would interpret this and how they would choose to present it to those individuals who supported them as well as to representatives of local services and other adults with Asperger's syndrome. These points will all be discussed in this chapter. As stated in the introduction, the research aims can be stated as:

1. To Use a participatory approach to explore how adults with Asperger's syndrome make sense of their experience of living in a neuro-typical world.
2. To reflect on the use of a participatory research approach with adults with Asperger's syndrome.

3. To reflect on how the principles of participation could be most usefully applied so that adults with Asperger's syndrome are more able to reflect on their experiences and express what they need from services.

**b) Assumptions about myself and the co-researchers that underpinned the research-My epistemological position**

The first research aim refers to experience and the 'making sense' of this experience. This is indicative of assumptions about myself and the co-researchers which underpinned this research. These assumptions related to my own view of experience, which is informed by interpretative phenomenology. Interpretative phenomenology is concerned with trying to understand personal lived experiences and interpretative phenomenological analysis (IPA) is concerned with exploring people's relatedness to phenomena (Smith et al, 2009). Phenomenology, according to Moran (2000) 'emphasises the attempt to get to the truth of matters, to describe *phenomena*, in the broadest sense of whatever appears in the manner in which it appears, that is as it manifests itself to the consciousness, to the experiencer' (Moran, 2000, p. 4).

My epistemological assumptions were that there is an external world to experience and that the co-researchers and I experience the world differently. Phenomenologists think that researchers cannot be detached from their own presuppositions (Groenewald, 2004, p. 7). I wanted to understand the experience of adults with Asperger's syndrome. I had considerable experience in supporting people with Asperger's syndrome and also had read a lot of the literature about autism. I certainly had many pre-conceptions about Asperger's syndrome and wanted to put these to one side and 'bracket off' my own assumptions of what their experience might be like (Giorgi, 1970, quoted in Dyson and Brown, 2006, p. 16). Taking an anti-positivist interpretivist position, I have assumed that people perceive a social reality and then act according to the meaning that they attribute to their actions and those of others (Bryson, 2008). According to Bryson, this leads to the point that 'it is the job of the social scientist to gain access to people's 'common sense thinking' and hence to

interpret their actions and their social world from their point of view' (Bryson, 2008, p. 16).

Although the literature had aided my understanding of how the discourse about Asperger's syndrome had characterised them as 'Other', the literature written by people with autism and my own experience convinced me that people with Asperger's syndrome tend to think in a different way to people who are neuro-typical. This added another layer of complexity, which I had not seen addressed in the literature about participatory research and this fitted in well with a phenomenological approach. Phenomenology, as Dyson and Brown (2006, p. 17) write,

...draws our attention to the extreme difficulty of really understanding one another, of the meanings we give to experience really being the same as the meanings others have.

The incongruity here is that I had to use my prior knowledge and experience to plan the research, before recruiting the co-researchers and then use it again to frame questions which I asked the co-researchers in order to create an enabling research space. One example is that I asked the co-researchers their preferred method of communication outside of the sessions, knowing that some people with Asperger's syndrome find phone calls cause them anxiety (this proved to be the case, with all three preferring emails as a way of contact). I had to utilise my pre-conceptions in order to work in an enabling way with the co-researchers. I would also use it to ask questions of the co-researchers to encourage a deeper analysis of the data. However, I acknowledge that I cannot know what it is to live in society as a person with Asperger's syndrome. Whilst I may have had pre-conceptions about what support people with Asperger's syndrome might want, I did try to 'bracket this off' and work with the co-researchers to facilitate them designing appropriate research tools and analysing the data in a way that made sense to them. For me, 'bracketing off' my pre-conceptions meant I tried to suspend them and be open to new ways of working and

understanding. I found that I had to create a way of using my expertise and experience to facilitate the work of the group whilst at the same time not imposing my neuro-typical assumptions on how the research was conducted or how data was analysed. This seems like a tightrope to walk as I had to differentiate between facilitation, contributing my own expertise and any imposition on the co-researchers. My view of knowledge and how this is generated was key to this distinction.

### **c) Knowledge generation-my epistemological position**

Mason (2002, p. 16) frames a question in relation to epistemological positioning-‘What might represent knowledge or evidence of the entities or social ‘reality’ that I wish to investigate?’ The epistemological position that underpins this research is an interpretivist one. By that I mean that the research is concerned with understanding the subjective meaning of social action (Bryson, 2008, p. 694). Knowledge is the expression of the experiences of social actors, how they make sense of the world, in this case, adults with Asperger’s syndrome. I was clear that one of the purposes of the research was to understand the experience of participants in the research (from data produced by the questionnaires and individual focus groups and interviews) through the lens of the experience of the co-researchers throughout all the research processes. IPA (interpretative phenomenological analysis) concerns ‘where ordinary everyday experience becomes ‘an experience’ of importance as the person reflects on the significance of what has happened and engages in considerable ‘hot cognition’ in trying to make sense of it’ (Smith et al, 2009, p. 33).

‘Hot’ or ‘emotional cognition’ is thinking that is influenced by factors such as motivations and emotions (Thagard, 2006, p. 3). Although IPA does not anticipate the use of co-researchers to take part in this emotional cognition, the appropriateness of this kind of reflection is consistent with IPA. I saw the potential of the co-researchers in contributing to the understanding of the data and hence the production of knowledge in two ways. Firstly, I viewed the need (and ability) of people with Asperger’s syndrome to systematise information (Baron-Cohen, 2004) to be an invaluable attribute in designing research tools and in coding the data. Secondly, I viewed the

potential of the co-researchers in responding to the data according to their own experience as essential to my methodology. I did not want the perspective of trained researchers, but of people who had the experience of having Asperger's syndrome and living in a neuro-typical world. This was fundamental to my view of knowledge production. Nind (2014, p. 73) discusses one of the criticisms of some participatory research as 'merely tinkering at the edges rather than transforming the social relations of research production' when compared to emancipatory research. Nind, referring to research with children, writes that one way in which this can happen is if the children or others involved in the research are 'deliberately or inadvertently-co-opted to adopt professional viewpoints'. Nind cites a view from an earlier publication (Nind et al, 2012, pp. 73-74) in relation to training 'lay researchers' that this can in fact result in teaching them to 'look at the world through our lens'. The lens that I wanted to use for knowledge production was that of the co-researchers.

There is a different danger in research that is based on this view of knowledge production and that is that the role of the non-disabled researcher can be minimised. I have myself tended to do this and it has taken some promptings from my supervisors to reflect on the role that I played. I was determined to highlight the role of the co-researchers and in doing so I sometimes disappeared altogether from my own accounts. This was a disservice to the role that non-disabled researchers can play in working alongside co-researchers. I will also discuss throughout this chapter the role that I played. My neuro-typical way of regarding the data and how the emerging themes could form a coherent whole was indeed as important in the formation of knowledge as the perspectives gained by the co-researchers. The richness and success of this research owes much to the combination of these two perspectives. The adoption of a research method based on the principles of participatory research enabled both perspectives to work together, and in so doing, to produce research which was truly co-produced.

#### **d) Choice of qualitative research techniques**



My choice of qualitative research techniques was in accordance with my epistemological position. My intention was to use methods of data generation that were sensitive to the social context in which the data was produced (Mason, 2002). I also wanted to have data produced that was 'rich, nuanced and detailed' (Mason, 2002, p. 3) and this again is characteristic of qualitative research (Mason, 2002). The epistemological assumptions underlying this research give the findings a credibility that it would not have if I had taken the view that I was the 'expert'. If I had taken the view that I, as a neuro-typical researcher, was able to observe or study the participants in such a way that I could conclude what was best for them in terms of support, then it would have amounted to a representation of my reality only. I would have taken the role of a powerful professional, knowing what was best for the participants. The research would have been far poorer. Relations of power would have been mirrored in the research process. The philosophical position that I took allowed for much richer research, which utilised the realities of adults with Asperger's syndrome at every stage of the research. This position allowed me to use my own experience and background and also to reflect on and make sense of the experience of others. It is to a description of this process that I turn next.

## **2. Co-creating an enabling research space**

In the Literature Review I discussed my intention to co-create with the co-researchers an autistic research space. It is this aspect of the research that I will now concentrate on. Building on the concept of participatory research as 'spatial practice' (Kindon et al, 2007; Nind, 2014), I wanted to co-create an enabling research space in which to investigate how adults with Asperger's syndrome choose to have a voice in the services that they receive. My aim was not to investigate this by myself but to investigate it together with a small group of adults with Asperger's syndrome. My own thinking was shaped by considering our research as spatial practice. Here, space is a metaphorical space. The metaphor is used to enable the conceptualisation of the research as an arena (as stated in Chapter Three) which can be governed by the 'discourses and practices of participation' (Kindon et al, 2007, p. 24). The group and I

working together co-created the research space. Within the space, we designed research tools, collected and interpreted data from other adults with Asperger's syndrome and planned and held a conference to disseminate our findings. Everything that happened in the research space was co-produced. However, there was preparatory thinking, planning and an application for ethical approval which I had to do before even meeting any of the co-researchers. Also, all of the reading, reflection and writing for this thesis was done on my own, with the support of my supervisors. So, although this thesis is about a co-created research space and co-produced research, it is not itself co-produced.

The stages in the research are indicated below in figure 2. The research space refers to the way in which the research was conducted. It relates to all the stages in figure 2 and is concerned with the *how* the research was conducted rather than *what* we did. I shall discuss both of these aspects in my discussion of each stage of the research.

a. Planning and gaining ethical approval



b. Recruiting co-researchers



c. Agreeing how the group would work together



d. Agreeing scope of research and designing research tool (questionnaire)



e. Distributing questionnaire and collecting data



f. Analysing data



g. Designing research tool for further enquiry (focus group and interview schedules)



h. Collecting data from focus groups and individual interviews



i. Analysis by co-researchers, using their own experience, supported by myself, with additional data being created in discussions



j. Dissemination of results at conference, with additional data being created from attendees



k. My reflection of and interpretation of this, based on my understanding from the literature and the academic social work discipline in which I am positioned

*Figure 2: Stages of Research*

Rather than continuing to refer to an 'autistic, co-created research space' (as referred to in Chapter Four) for brevity, I shall henceforth refer to this as an 'enabling research space'. However, in the context of this research I mean that it was co-created and that it was also an 'autistic' space as previously discussed in the Literature Review.

The group, consisting of myself and the three co-researchers with Asperger's syndrome met for 32 whole day sessions between 16<sup>th</sup> April 2010 and 21<sup>st</sup> June 2012. In addition, I met with individual members, sometimes on their own and sometimes with a parent to work on their individual contributions to our conference. These were extensions of our research space as we worked together in the same way as agreed in our group and included parents in this. Table 1 below shows a timeline of the research.

<b>Date</b>	<b>Activity</b>
<b>July 2009</b>	Discussions with Asperger's Team about the principle of conducting some research-they agreed to ask local support groups if I could attend to talk about the possibility of conducting research
<b>26<sup>th</sup> August 2009</b>	Attended support group to ascertain interest
<b>January 2010</b>	Ethical approval gained to recruit co-researchers
<b>January –April 2010</b>	Recruitment of 2 co-researchers
<b>16<sup>th</sup> April 2010</b>	First meeting and agreement of how the group would work together
<b>April to July 2010</b>	8 whole day sessions with the 2 co-researchers agreeing the scope of research and designing research tool (questionnaire)
<b>July-August 2010</b>	Piloting of questionnaire
<b>18<sup>th</sup> August 2010</b>	Meeting with third co-researcher and family following recommendation from social worker
<b>27<sup>th</sup> August 2010</b>	Third co-researcher joined the group
<b>6<sup>th</sup> October 2010</b>	Ethical approval gained for questionnaire stage of research
<b>October 2010</b>	Letters sent to all 'known' adults with Asperger's syndrome in the area where we were working giving them information about the research and the questionnaire put live on the web

<b>6<sup>th</sup> January 2011</b>	I attended a team meeting with the Asperger's team <sup>2</sup> and they agreed to give their service users copies of the questionnaire if they wanted to take part in the research to aid with questionnaire return
<b>January 2011-March 2011</b>	I contacted local services to encourage a wider response rate to the questionnaire
<b>October 2010-August 2011</b>	10 whole day sessions with the co-researchers analysing the data from the questionnaires and the start of planning for next phase of the research
<b>10<sup>th</sup> August 2011</b>	Finalisation of the three main themes from the data
<b>August 2011 to September 2011</b>	2 whole day sessions to develop the questions for the focus groups and individual interviews based on the three main themes from the data analysis of the questionnaire
<b>30<sup>th</sup> September 2011</b>	Ethical approval gained for focus groups and individual interviews
<b>October 2011</b>	Focus groups and individual interviews
<b>October 2011-May 2012</b>	Analysis of data from focus groups and individual interviews and planning of conference

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<sup>2</sup> The Asperger's team were a County-wide team of social workers in the area where the research was carried out. They supported adults with Asperger's syndrome between the ages of 18 and 65.

*Table 1: Timeline of the research:***a) Planning and ethical approval**

Crucial to this research was the formation of an enabling research space and the recruiting of a group of co-researchers to work alongside me. The learning from the literature in relation to the formation of an enabling research space informed every aspect of the co-creation of this space. Initially, the thinking was done by myself with support and contributions from my supervisors. I submitted an ethical approval application which was granted on 20<sup>th</sup> January 2010. This application and my preparation for recruiting people with Asperger's syndrome to co-create this research space were concerned with outlining clearly the nature of the proposed research, obtaining consent and providing information about my own competence (Appendix 1). I will discuss the ethical issues as they pertain to each stage of the research in my account of each stage below.

**b) Recruiting co-researchers**

My first concern was how to recruit co-researchers. I had the intention of developing the research space with the co-researchers and of finding ways to work together as a group which were positive to them and did not merely favour my own neuro-typical preferences. I was aware that some adults with Asperger's syndrome would find any form of group work quite difficult. I wanted to recruit co-researchers who would be willing and able to work with me to develop suitable working methods. Part of my ethical considerations was to avoid causing any unnecessary stress to the co-researchers from processes that related to the research. As mentioned in the introduction, I had worked as a social worker for a local authority and when I approached this authority, they gave me some very useful introductions to individuals with Asperger's syndrome and to a support group for adults with Asperger's syndrome and their carers. There were four support groups in the area that were funded by the

local authority-all were approached by social workers to see if I could attend to talk about the proposed research. Only one was willing for me to attend. I visited the support group to talk about my proposed research. The individuals that were suggested were people who, in the opinion of their social workers would not find the process of working in a group prohibitive to being co-researchers. They would also be interested in the opportunity to work with other adults with Asperger's syndrome. This of course meant that neuro-typical workers had a role in suggesting co-researchers in addition to people with Asperger's syndrome being approached directly. I met with two individuals who the council's specialist Asperger's team thought would be interested in being a part of the group. One of these joined the research at the beginning and the other about six months later. I had an open approach to the recruitment of co-researchers. No one who expressed interest was screened out.

The support group that I talked to was attended by adults with Asperger's syndrome, some of whom found working in a group quite difficult and some of whom were more comfortable with it. The group was organised by a social worker and a community worker and from my observations the sessions were dominated by the parents discussing their perceptions of the services that their adult children received. I attended the support group a number of times and outlined my idea for the research. I asked if anyone wanted to take part in this project with me. My reception at the support group was positive and several people expressed a desire to be a part of the research. There was some concern expressed by carers that the group did not include them but I explained that although I recognised the importance of carer views, these might differ from those of adults with Asperger's syndrome and I wanted to find out what they thought. This was accepted and the principle agreed that if any adult with Asperger's syndrome needed to be supported to attend the group this would be an exception. In this case, the carer or supporter would be there to do just that, support the individual with Asperger's syndrome and not participate themselves. The support group was attended on each occasion by five young adults with Asperger's syndrome,

three parents (all mothers) and one male partner of one of the young women as well as the two professionals already mentioned.

I was asked about my motivation for wanting to conduct the research by one of the adults with Asperger's syndrome. I explained that I was interested in working with people with Asperger's syndrome as a professional but also for personal reasons as I have a number of family members with Asperger's syndrome, including my son. I also explained that the research would contribute to my PhD thesis and would give me the opportunity to try to form a research group with adults with Asperger's syndrome in a way which, to my knowledge had not been done before. I thought that it was important to be open about my motivation; I was mindful of the literature discussed in Chapter Four about reciprocity (Zarb, 1992; Oliver, 1992). I wanted to start with being open about my own personal as well as professional interest in conducting the research. This proved important as the person from the group who did become a co-researcher said it was the fact that I am a mother of a young person with Asperger's syndrome that reassured her about attending the group, not my professional experience or qualifications. The co-researcher later explained that her opinion was based on her lack of trust of many professional workers. She felt that professionals had worked with her in unhelpful ways in the past and so she had 'lost faith' in neuro-typical professionals.

I had intended to use the concept of space to help me plan and evaluate the research. However, I did not discuss the concept of 'space' with the group until much later in the research. Instead I talked about forming a 'group'. As I knew that people with Asperger's syndrome can be very literal in their thinking, I thought it would be unhelpful and possibly confusing to them to introduce a metaphorical concept, especially at a very early stage of working together. However, the principles involved in co-creating an enabling research space were discussed with them.



One individual I had met separately following a recommendation from his social worker had said that he could meet on any date. I was therefore able to agree with the group a date, time and venue for the first meeting about the research, to which everyone with Asperger's syndrome from the support group I had visited was invited. I was very aware that some adults with Asperger's syndrome do not like to have demands put on them to commit to a particular activity, for fear of making a social mistake (Attwood, 2007, p. 140). Rather than ask people to agree to be a part of the research group at the support meeting, we agreed a date and time where everyone in the group could attend in principle and it was left to them to come if they chose to. I was not certain if anyone would attend from the support group or if they would all attend. I was not sure at that time what would be an appropriate number of people to be in the group and in fact even if I had, this would have been difficult to achieve with the invitation being left so open. Although this method of recruiting co-researchers from the support group may seem tentative, it was my view that it was necessary to work in this way and give people an open invitation which they could accept on the day I met with the support group (which many did) but make their own decision about taking part and not attend our first session if they did not want to. I made it clear at the meeting that all were welcome but that it was perfectly acceptable for people to opt out. My prime concern was not to create a stressful situation for people, which seeking a commitment to attend could have caused.

#### **c) Agreeing how the group would work together**

I drew up an information sheet and consent form (Appendix 2) and draft proposal which outlined the responsibilities of the group as well as my own responsibilities towards the group. This was in fact very helpful at the first meeting as it generated some good discussion about how we would work together. Attwood writes of how difficult it can be for people with Asperger's syndrome to work in a group:

I have noticed that people with Asperger's syndrome may function reasonably well in one to one interactions, using their intellectual capacity to process social

clues and non-verbal communication, and using memory of similar social situations to determine what to say and do. ...In a group setting, the person's intellectual capacity may not be sufficient to cope with the social interactions of several participants, and the person may take longer to process social information that is normally communicated more quickly in a group than individually (Attwood, 2007, p. 56).

I would take issue with Attwood's use of the term 'intellectual capacity' as this is quite a medical model view of Asperger's syndrome. Instead I would prefer the term 'intellectual differences' as it is the way that people with Asperger's syndrome think differently that makes it difficult for them to work in groups. However, the fact that people with Asperger's syndrome generally find it difficult to work in groups is not disputed.

At the first meeting two adults with Asperger's syndrome attended, a man and a young woman. I had already met the man as noted above and the young woman was from the support group. Although I was initially a little disappointed that the group was not larger, time proved that a small group worked very well. When the third person joined, the co-researchers asked that the group remain that size. I think that the size of the group and the fact that it built up from two co-researchers to three made it easier for the co-researchers to function well in the group, bearing in mind Attwood's point above about the difficulties that people with Asperger's syndrome can experience in a group setting.

The group later chose that I use their names in any publications, including this thesis, as they want to be identified with the project. The group consisted of myself, Katrina Fox, Duncan MacGregor and Laura Hickman.

As part of the ethical approval I had to address how I would generally engage with the group, but in reality I was not sure how this was going to work in specific terms. I cited

my own experience as a social worker and explained that I was aware that different people with Asperger's syndrome would have different communication preferences and that I would conduct any meetings in a way that met these needs. I knew my best strategy was to listen to what the people in the group said and not necessarily use models of engagement that had worked for me in the past. I knew I wanted to co-create an enabling research space, but I had to engage with the co-researchers in such a way that was conducive to this developing. None of co-researchers knew each other previously. I was concerned to find with them a way that everyone in the research space could feel comfortable and be able to work together. I wanted to work in a way which was 'autism friendly' without being totally sure what that was in a group situation.

What I found was that Katrina, Duncan and Laura are three very different individuals with very different needs as well as strengths. I discussed with the two original co-researchers at the beginning how we could work together. It became clear that the best way to work together as a group was to let each play to their strengths and not put any demands on the co-researchers which they were not comfortable with. As I have a background in working with people with a learning disability and had worked to support adults with a learning disability to take on roles of responsibility it felt natural to me to encourage one of the group to chair our meetings. I quickly learnt that this was not the right approach to take with this group. I learnt from the group members that this would indeed be an unwelcome approach. Our initial task was to find a way of working which suited their skills, preferred ways of communication and perhaps more importantly did not raise their anxieties. This way of working evolved over time. Initially it was with me recording their views as expressed in meetings on flipchart paper and turning them into typed records of the meetings. I then emailed these to the group for their comments and agreement. As I and the co-researchers became more confident, I started to take my laptop into sessions. Initially I recorded summaries of what they wanted to say and checked with them whether they were happy with my recordings and amended as appropriate during the sessions. This was

initially in the form of notes of our meetings and later became their thoughts about the data analysis. After a while I asked the co-researchers if they would like to take it in turns to type summaries of the group's thoughts and decisions directly onto the laptop. They did want to do this. This method of recording our discussions removed the stage of me interpreting what they wanted to say. Although it was me who actually facilitated the meetings, I was confident that they were taking roles they were happy with rather than being shaped by what I had previously considered to be the best way to practice.

None of the literature I had read at this stage in my research was about participation and participatory research which involved people with autism or Asperger's syndrome. I have discussed how the literature identifies control as a crucial and deciding issue for identifying what type of research is being conducted. I had to review my own views on control in the co-creation of this research space as I realised that my perceptions were neuro-typical. I had conceptualised 'control' as chairing meetings, summarising discussions and conclusions and deciding on the agenda of sessions. For the co-researchers this was not the case. For them, control was in effect defined as being able to take part in the way that they chose and not being put under any pressures as a result of the activities that we engaged in. I chaired all sessions throughout the time we were conducting the research. After discussion with the co-researchers, we found that the best way of deciding what to do in each session was for me to present alternatives and they give their view on this. In this way we set the agenda, by reviewing what we had been doing in previous sessions, what there was left to do and agreed an appropriate order for work as well as the timescales in which we wanted to complete the work. We also developed a predictable format to the sessions, keeping all sessions starting at 10.00 am with a lunch time at 12.00 to 1.00 pm and finishing at 3.00pm. We always met at the same venue, which was a self contained room in a community centre, minimising external stimulation, thereby facilitating concentration for the co-researchers. Each co-researcher chose to do exactly the same thing every lunch time with one walking their dog, one going to the same pub for a drink on their

own and one sitting in the community centre café, chatting to me. All these elements were partly arrived at through agreement and partly, as with the lunchtime routines, through the individual decisions of the co-researchers. The end result was a format which was comfortable to all as, apart from the actual work itself, it ensured a great deal of predictability. One of the group members described dealing with unexpected situations as having to cope with 'too many variables' and part of our co-created research space was to have as few variables as possible.

As noted in the Literature Review, emancipatory research is based on the social model of disability. I discussed the social model with the co-researchers and its use to inform how we worked together. I introduced this as a concept in our second session. It might have been more useful if I had introduced this in the first session as an underpinning philosophy to my understanding of the research we were embarking on. However, I did not do this and instead introduced it as a concept in relation to comments that were made by one of the co-researchers who referred to 'normal people', by which they meant people who did not have Asperger's syndrome. The co-researcher who said this described how they thought their 'life was over' when they were diagnosed as having Asperger's syndrome. I believed this was an important moment and we stopped the work we were doing to consider the comment. The literature discussed in the Literature Review highlights the need for reciprocity in research as well as the willingness of the researcher to put their skills at the disposal of the co-researchers in emancipatory research. I thought it an important principle to use my knowledge to the advantage of the co-researchers and not just in the process of working on the research. I was mindful of the criticisms in the literature that researchers left co-researchers no better off after they had completed their research. I did not want to do this. I thought that the low self esteem expressed was a result of the oppressive nature of society and I was committed to co-creating a research space with the group that addressed issues of power. I therefore used my knowledge of how society disables and oppresses groups within it in discussions with the co-researchers about how they felt about having Asperger's syndrome.

**d) Group name, agreeing the scope of the research and designing research tool**

At the first meeting I asked the group what we should call ourselves. The co-researchers chose the name 'Aspergers Consultation Group'. The proposer of this title said they wanted to be identified as adults with Asperger's syndrome and also wanted it to be known that they had indeed been consulted. We discussed how we were going to find out about what other adults with Asperger's syndrome thought about the support that they were receiving and thought they needed. To assist me in discussing the scope of the research with the co-researchers, I made a note in advance of the session of some questions that I wanted us to consider together:

- What do we want to know?
- Is research with adults with Asperger's syndrome different from research with other people?
- What other differences are there in relation to people with Asperger's syndrome?
- How do we ensure we work in a way that allows for any differences?
- How can we maximise our chances of success?
- How do we know which approach is best for individuals? Which would you prefer?
- Can we include everyone? Who is 'everyone'?

The discussion that this prompted was useful both for the methodology in terms of the research instruments we decided to employ as well as helping to ensure our 'research space' was based on the social model of disability. The first question provoked discussion about the difference between people with Asperger's syndrome and 'normal people'. We discussed the term 'normal people' and agreed to refer to 'neuro-typical people' instead, as suggested by one of the co-researchers. One of the co-researchers expressed the view that neuro-typical people have 'fuzzy thinking'. The co-researchers had a view that people with Asperger's syndrome think in a different way (as also evidenced in my Literature Review) and this meant that research with people

with Asperger's syndrome might be different to research with neuro-typical people. I was not sure in what way this would be the case. Through discussion, we decided that it might be different in terms of how people are contacted and participate. This meant that it was important to choose an appropriate means of engaging with possible participants. We also wanted to reach as many people living in the area as possible. Through our discussions and in considering the other questions, we concluded that the best way of collecting data was by means of a questionnaire. This means had the potential to include a lot of people and would not be threatening to participants in the way that face to face contact could be.

**i) First thoughts**

We wanted to give people every opportunity to be able to complete the questionnaire so we agreed to make it available by email, through the internet, as a hard copy which we would post to people or by meeting with them to complete it together. It is interesting that we discussed how we were going to conduct the questionnaire before we actually decided what we wanted to know. On reflection, I think this was driven by an anxiety of mine to get the process right and so this was the early focus of our discussion. When we discussed what the focus of the questionnaire should be, I was concerned with not leading in a particular direction but with finding out what the co-researchers thought the priority areas were within the scope of our enquiry. I asked what issues the group thought were important in relation to services and made a list of them all on flipchart paper. We ended up with quite a long list and I thought this was too large a scope for one questionnaire. I encouraged the group to consider reducing the list by asking them what topics were the most important. This was not a very successful strategy on my part as it did not result in any comments from the co-researchers. On reflection I think this was because the question was a value based one and I had not supplied a rationale for this decision. I tried a different tack. One of the areas identified that the group were not happy with was in relation to the benefits system in England. One member of the group thought that the benefits system was an important area. They stated that in one support group for adults with Asperger's

syndrome they had attended this was the most talked about topic. I noted in Chapter Four Byers' (2005) caution about being honest about what can be achieved in research. I knew that the benefits system would be a really difficult area to have any influence over at all so I asked 'what are the topics which you think we are most likely to be able to influence when we have finished our research?' This led to the co-researchers reflecting on the topics, using this as the criterion to choose which topics to focus on. They thought that we were unlikely to be able to influence the benefits system and so decided to concentrate on topics which were connected to local services. This approach was more effective and it encouraged the group to think ahead to any findings and whether or not they thought there was any potential for change. This became typical of the role that I played in the group as I did steer their decision making by asking questions for them to consider. Had I not asked that question, the project might have looked quite different. Diagnosis was the topic which the group was most interested to explore and so we made this the first topic in the questionnaire after a more general section asking for personal details such as age group and gender. In discussion, it became clear that there was not total agreement about the implications of diagnosis on how the co-researchers felt about themselves. One co-researcher was concerned to investigate how people felt after diagnosis, whilst another member did not feel this was as important. We spent several sessions deciding on the categories for the questionnaire, the actual questions under each section and the order of the sections. The discussion was always focused around the experience of the members of the group and what was important to them.

## **ii) Why a questionnaire?**

In research generally, issues of questionnaire design are given careful consideration as part of 'good practice' as with all issues of design. Questionnaires often use standardised questions and utilise design principles. In this research, the methodology meant that it involved untrained co-researchers who had no background in understanding issues of validity relating to design. However, the process we undertook actually increases rather than diminishes the validity as the co-researchers have an insight into the ways that other people with Asperger's syndrome interpret questions that neuro-typical people cannot possess.



The choice of a questionnaire was based on a number of factors. Firstly, we decided to use the experience of the co-researchers which would enable us to determine the aspects of support which were important to investigate, being consistent with a phenomenological approach (Smith et al, 2009) and principles of participatory research (Oliver, 1990). Secondly, the co-researchers felt that other adults with Asperger's syndrome may prefer to complete questionnaires rather than be interviewed face to face. Thirdly, we decided that this was the best way to reach as many people diagnosed with Asperger's syndrome living in the area of the local authority who were supporting us.

Other research involving adults with Asperger's syndrome that I have since read about did not use questionnaires. One study (Bagatell, 2007) used observations of and interviews with an individual with Asperger's syndrome, the scripts of which were then checked out with the participant. Another study (MacLeod et al, 2013) used interviews with participants with autism and Asperger's syndrome where the participants were given the opportunity to comment on the analysis of the data. One of these studies was with one person and the other with ten. I knew that questionnaires have low response rates (Denscombe, 2007) and discussed this with the co-researchers. However, we thought it was important to give everyone we could contact in the area the opportunity to be a participant. We wanted people with Asperger's syndrome to be able to select whether they wished to be part of the research, rather than us approach selected individuals. We discussed principles for the questionnaire design and agreed on the following:

- Language will need to be clear and direct.
- There will be no visual clues in any questionnaires as these seemed patronising.
- The age group we consult should be 18-65 (the group chose this age group as it was consistent with how services in the area are organised).

### **iii) Diagnosis and the questionnaire**

We discussed whether someone should have a formal diagnosis of Asperger's syndrome in order to take part and decided to state that we wanted to consult with those who 'have a medical diagnosis from a professional'. The group reasoned that there might be people who think they have Asperger's syndrome and may or may not be correct. The co-researchers thought it was important to consult with those who were sure that they have Asperger's syndrome. They thought that if people took part who did not have a diagnosis, then the data could be corrupted. The criticism could be levelled at us that we accepted the medical diagnosis of 'Asperger's syndrome'. However, for a number of reasons, it was important to the research that this categorisation was allowed to stand. Firstly, the group was formed on the basis of recruiting people with this diagnosis. Secondly, the co-researchers felt it was important to their own sense of identity. Thirdly, it would have been extremely difficult to recruit participants without the clarity that this classification allowed.

#### **iv) Questionnaire composition**

The questionnaire consisted of seven parts (Appendix 3). The group discussed and agreed the questions as well as the options for responses. The way the group selected the focus of the questions will be discussed later in this chapter. The questionnaire used a mixture of open and closed questions. The closed questions offered a choice of responses. Some of these questions offered choices which group possible answers together, for example, question 2 in Part B asked about the age at which the participant was diagnosed and the options offered were age ranges. Other questions had choices which were based on the Likert Scale (Denscombe, 2007). An example of this is question 1 of Part D which asks 'Do services help you deal with the outside world?' and a range of choices was offered: 'not at all', 'they help a little' and 'they help a lot'. An additional response option was offered to this question which is not based on the Likert Scale: 'I don't receive services'. The group decided that we wanted to ensure that questions were not left unanswered as we would not know how to interpret that- it could be for example that it did not apply to the person concerned or

that they did not answer for some other reason. The inclusion of this option meant that we could ascertain if the question did not apply to participants.

The questionnaire was structured by being divided into seven parts, A-G. The first section (Part A) was designed to determine some demographic information about the participants. The second section was concerned with the experience of diagnosis. The next four sections were dedicated to areas where the group thought adults with Asperger's syndrome might need support. They were called 'Interacting with People', (Part C), 'Dealing with the outside world', (Part D), 'Access to work' (Part E) and 'Work' (Part F). The last section (Part G) was entitled "Other information" and consisted of one open question. Questionnaire respondents<sup>3</sup> were asked to write about 'anything about services which you think is important that the questionnaire hasn't addressed'.

The group decided that we would use the same formula for the initial question in Parts C to E. We asked whether services helped the respondent in the area that each section focused on, for example Part C, question 1 asked 'Do services help you relate to people?' Each Part then had questions designed to ascertain how services were helping in that area and what improvements could be made to services to support the respondent better. Part E, 'Access to work', asked about what was helpful or unhelpful about any support, what was missing from support and, if the respondent had not received support in accessing work, what support they would like to have had. Part F, 'Work', asked what types of work the respondent had done and if they had worked and had support in work what had been helpful and unhelpful. All of the questions in Parts C to G which asked for judgements about the support respondents received from services were open questions, allowing the respondents to say whatever they wanted. The group had discussed how these questions should be framed. We decided that questions asking for a judgment about services should be open questions as we wanted the respondents to be free to respond in any way they chose. Any options we devised would limit the data and potentially we could have lost very important

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<sup>3</sup> I have used the term 'respondent' for people who completed the questionnaires and 'participant' for people who took part in the focus group and individual interviews.

themes. Although the co-researchers were adults with Asperger's syndrome we did not want to assume that other adults with Asperger's syndrome would have the same opinions or experiences as them. The use of open questions was a conscious decision to ensure the data would represent the views of the respondents rather than those of the group.

**v) Piloting the questionnaire: Ensuring the questionnaire was 'autistic' friendly**

Although the process described above demonstrates that it was the co-researchers whose views formed the scope of the questionnaire, we wanted to ensure that the sections we had chosen were relevant to other people with Asperger's syndrome and also that the wording was understandable and not patronising in any way. We agreed to pilot the questionnaire. We did this by each taking a copy of the questionnaire away and asking other people to look at it to see if the wording was understandable and was pitched at the right level. Between us we consulted other adults with Asperger's syndrome, both individually and as part of a support group, as well as carers and professionals who support adults with Asperger's syndrome. This was a very useful process as it did highlight some issues for us to address. The group discussed the feedback and decided whether to change the questionnaire in response. In all cases we decided to amend the questionnaire as the group did indeed agree with the points made. As one of the main concerns in our design of the questionnaire had been to make it 'autistic friendly', we took particular note of any suggestions in relation to the wording from other adults with Asperger's syndrome. Originally we had a section which we had called 'navigating the outside world' as the group had thought this accurately described their tasks in daily life. This had also made sense to other people with Asperger's syndrome that we had talked to informally at an earlier stage. One person with Asperger's syndrome had actually talked about needing an internal 'satnav' in order to survive in the community. However, it became clear in the feedback that this did not make sense to everyone, so we changed it to 'dealing with the outside world' as this seemed to be more universally understood. We took the

revised questionnaire back to the people who had commented on it and they agreed with the changes that had been made.

The literature on questionnaires highlights both their advantages and their disadvantages. Greener (2011, p. 39) refers to them as the best and the worse of social research. He writes that they are almost impossible to get right as different 'subjects' respond differently to different words and concepts and also they offer only one chance to ask the questions. We tried to address some of the pitfalls of questionnaires in our design as described above. Bryman (2008, p. 217) discussed the different between self completed questionnaire and semi structured interview and concludes that they are very similar methods. The obvious difference being that there is no interviewer present in self completed questionnaires. However, Carey (2009, p. 24) does allow for questionnaires can be completed by a researcher in the company of a respondent. As noted above, both methods were practiced. Some questionnaires were completed by the respondents and returned with no actual contact with myself or the co-researchers and other respondents were supported by me and asked that I complete the questionnaires for them by recording their verbal answers. The effect could have affected the data that was obtained as Bryman (2008, p. 218) writes that the characteristics of an interviewer can affect answers that people given. He states that this effect is eliminated in self completed questionnaires. This means that the self completed questionnaires that were received were free of the effect that I could have potentially had by the way that I asked questions to those who I supported. However, it was necessary to give people the option to receive support to meet their needs and to ensure that we obtained as much data as possible. As Bryan (2008, p. 218) states, a disadvantage of self completed questionnaires is that there is no opportunity for prompts or probes and this can result in missing data (Bryman, 2008, p. 219). Data could have been missed as a result of the self completion method, whereas this was not the case when respondents were supported, but there was the different risk of influence.

We designed the questionnaire in line with principles of good questionnaire design. Carey (2008, p. 125) outlines what makes a good questionnaire and the list includes:

- Offer simple and brief instructions on how to complete and return the document
- Be clear, ambiguous and easy to understand

- Link clearly with research aims and objectives
- Avoid 'leading' questions

We did provide clear instructions on completing the questionnaire and gave option for different ways to complete it. We had tried to use language that was unambiguous to people with Asperger's syndrome through our piloting. The questions were designed to find out the views of people with Asperger's syndrome on services that they received. We tried to provide clear rather than leading questions and offered options for answers that didn't lead, but allowed for a full spectrum of answers.

Layder (2014, p. 100) writes that the overriding issue for a questionnaire is to achieve clarity for the respondent and that is what we tried to achieve, through the wording of the questions and through the order in which they were presented. Carey (2009, p. 126) explains that the sequence of questions in a questionnaire is important and should gradually explore the topic over the course of the questions. We explicitly considered and reflected upon the order of the questions as we thought this to be especially important to adults with Asperger's syndrome due to their preference for systemising (Baron-Cohen, 2004). We started with information about the respondent and moved onto how they experienced the world, then the world of work. We ended with a section asking for additional information they would like to add. This order was thought to be logical by the co-researchers, although we did not ask this when we piloted the questionnaire. On reflection, it would have been helpful to have more explicitly addressed this at the piloting stage to ensure that this order was helpful to other adults with Asperger's syndrome other than the co-researchers.

#### **e) Distributing the questionnaire and collecting data**

Ensuring the questionnaires reached people with Asperger's syndrome who lived in the area of the local authority with whom we were working was not a straightforward process. The task needed to address two ethical issues: accessing the appropriate people without the local authority breaching data protection regulations and contacting people in a way which did not cause anxiety. I met with the local Asperger's syndrome team to discuss how to proceed. This team had been very supportive of the research from its conception and had been part of the piloting of the questionnaire.

They had also supplied me with the contact details of the support group I attended, to recruit co-researchers as well as the contact details of the two of the co-researchers. To address the first issue, we decided that the team would initially write a letter to all the adults with Asperger's syndrome on their database rather than send out the questionnaire. The letter told them about the questionnaire and explained that it was not produced by anyone from the council. It also said that the Asperger's team supported the research. This was thought to be important as the team said there were people who would be very anxious about any questionnaire that came from the council and worry that it would affect them adversely in some way if they responded. This also addressed the issue of data protection as it made clear that I would never have access to the database of names and addresses as it was the council that had sent out the letters. The team also felt that an actual questionnaire arriving through the post would cause anxiety for some of the people that they supported. In order to avoid this happening, we decided that the group would design a flyer to put in with the letter telling people how they could access the questionnaire (Appendix 4).

Having met with the Asperger's team and agreed the principles I then met again with the co-researchers to discuss the flyer and how to make the questionnaire accessible. Contact details were given on the flyer for email contact, postal and phone contact. I knew through what the group had told me and from the literature that phone contact is often difficult for people with Asperger's syndrome. As a result, I did not anticipate much phone contact but I did not want to make an assumption that nobody would want to make contact in this way. Instructions on how to access the questionnaires in all these forms were put on our flyer and the group wrote a letter to go with it explaining what the research was about and about us as a group. The letters and flyers were sent out to over 200 adults with Asperger's syndrome. A local charity supporting people with autism also put a link to the questionnaire on their website. In order to try to increase the number of participants, I also contacted residential services, colleges and schools in the area where I thought people with Asperger's syndrome might be placed, to tell them about the research. The Asperger's team also agreed to take the

flyers with them when they made visits to people and leave them with a stamped addressed envelope (which I supplied) so they could choose whether they wanted to respond or not. We had thought that the majority of responses would be via the web as the co-researchers thought that adults with Asperger's syndrome are often comfortable with this medium as it does not provoke anxiety in the way that face to face interactions can. However, what was surprising is that while some did respond in this way, this was not the main way in which people took part in the research and many responses came through the personal contacts that I made. This resulted in me visiting some residential units and going through the questionnaire with people and writing down their responses on their behalf when they asked me to do this. I did not do this with a co-researcher as I was asked to come alone by the respondents. This preference was expressed to me by the staff who supported them so I confirmed with the individuals concerned that they did indeed want me to support them in completing the questionnaires.

#### **f) Analysing the data**

We received 19 responses to the questionnaire out of more than 200 contacts, which resulted in much data to analyse. My concern was how to do this with the group for, as with every other stage of the research, we agreed that this should to be done collaboratively. We met regularly during the period of waiting for questionnaires to be returned and rather than look at them all at the same time, we considered them as we received them. We recorded each response on a document, which we kept updating, where we cut and pasted every answer and put them in columns for each question. In this way we could look at both the whole questionnaires and all the responses that were received for each question. I had read of other collaborative research where service users had not analysed the data but where this task had been carried out by academic researchers who then presented 'emergent themes' to the service users to consider (Tew, 2008). Tew has reflected that this was a cause for concern as important data may have been overlooked due to the particular 'standpoints and perspectives' of the academic staff (Tew, 2008, p. 282). I suggested to the co-researchers that they



could look at the data outside of our meetings, as I did not want to unduly influence them. However, they did not want to work in this way-they wanted to work as a group. This proved to be an important decision as the data was analysed in a way which was a result of the collaboration between us. Nind (2011) refers to 'collaborative sense making' (Nind, 2011, p. 357) when discussing participation in data analysis. She cites Nicholls, who identifies this process as a reflexive one that is a 'theoretically consistent tool within participatory methodology' (Nind, 2011, p. 357). Nind links this with 'debates about who can know whom, whether we are 'transparently knowable' to ourselves...and to others like us' (Nind, 2011, p. 357). I am aware that our way of looking at the data together was helped by the relatively small number of questionnaire responses to consider. Had we had many more responses, we would have had to consider a different way of working together.

Our concern was to make sense of the data as a group. We worked from the premise that the co-researchers, as people with Asperger's syndrome would be key in making sense of the experience of other people with Asperger's syndrome. In other words, we recognised the role of the identity of the co-researchers in the data analysis. We did not discuss the role my identity played in the research production but on reflection, my identity as a neuro-typical person did also play a significant role in the analysis as elsewhere in the research. It was the combination of the understanding and systemising of the data from the co-researchers with my facilitation of this, asking questions which furthered the analysis and my own understanding of the significance of the analysis and it's fit into existing ideologies that enabled us to frame the data in the way that we did (as will be discussed in the next chapter).

The co-researchers decided that they wanted to look at all the answers to each question and discuss each in turn, rather than look at individual questionnaires. We read each response and the group decided what they thought was the 'message' that it contained. This was achieved by creating a summary statement and this was written down. This accords with Saldara's (2013) explanation of coding as 'a word or short

phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language based or visual data' (Saldara, 2013, p. 3). The group discussed the wording for each code, sometimes using the words of the respondent and sometimes using the experience and understanding of the group to interpret what was being said. For example 'understanding neuro-typical behaviour' was a summary statement that the group devised and we used it as a code. In this way we built up a list of codes (Appendix 5). Each time we met to look at new responses we used these codes to categorise the responses and added further ones to cover new codes which the group felt were not already covered. Some questions were answered very precisely by the respondents while others were felt by the group to have missed the point of the question and so the group decided to discount these responses. This was a decision with consequences for the analysis as there may have been further codes that could have emerged which we did not identify and so there may well have been areas that we did not consider together. I could have asked that we also look at these responses and code them, but did not do so. It was apparent to me that the co-researchers were operating in a very systematic manner and this did not allow for responses which were outside the intention of the original questions. I recalled Baron-Cohen's work on the extreme male brain as a description of autism and the need to systematise (Baron-Cohen, 2004). I did not feel it appropriate to influence the categorisation in this way as this is how it made sense to the co-researchers and that is the perspective that we wanted for the analysis. This, I regarded as being a part of co-creating an enabling research space, as we adopted the preferred ways of working and thinking of the co-researchers. It was also part of me 'bracketing' myself off within the research and adopting a phenomenological approach.

The co-researchers had different preferences as to how the data analysis should be presented. I suggested that we use different coloured highlighters to represent the different codes but they did not think this was helpful. Two co-researchers wanted the responses to be listed under the different codes whereas one co-researcher wanted the response to be categorized numerically. In order to make sense of the data, this person worked on the data outside of the group and assigned each theme a number

and placed it in a spreadsheet. For this particular co-researcher this was an important process as it made the information more accessible and comprehensible to that individual. That co-researcher was then able to bring the spreadsheet to sessions. This is an example of how different techniques were used to suit individual ways of understanding. Certainly a 'one size fits all' approach would not have worked even within the group of co-researchers.

As we were working on the formation of the codes, the group discussed and made a note of what they wanted to explore further in the next phase of the research. Diagnosis was a recurring theme that the group discussed. Each member of the group had a very different experience of and reaction to their own diagnosis and they discussed this with each other, sharing their own experiences as they read the responses to the questionnaire. Many responses had resonance for the co-researchers, for example when respondents said that they had felt misunderstood, the group shared examples of when they themselves had felt similarly. This was sometimes in relation to humour and sometimes when they had been misinterpreted as being rude by others. One of the topics which created the most debate was whether people with Asperger's syndrome considered themselves to be disabled or not and whether having Asperger's syndrome gave rise to a positive or negative sense of identity. These were two of the questions which went forward to the next phase of the research.

***i) The social model of disability and data analysis***

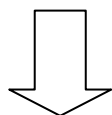
The discussions in the group relating to the data analysis and what they wanted to focus on in the next phase of the research gave rise to further discussions about how individuals in the group felt about their own identity. It was clear that for at least one member, having being diagnosed with Asperger's syndrome had been a very negative experience and this was often expressed with regret and a sense of loss. I wanted to continue to co-create an enabling space so I encouraged discussions about the social model of disability during this stage. As already noted, I had explained what the social model of disability was during our second meeting and that this was the approach

which underpinned the way I wanted us to work together. I had explained also that they were the ‘experts’ and that my expertise came in the research process and in working with groups. This distinction had pleased the group. We had many discussions about what it means to have Asperger’s syndrome and about *difference* as opposed to *deficit*. These discussions were important to individual members as they used the group to explore for themselves what it meant for them to be an adult with Asperger’s syndrome. It was inevitable that the discussions around the experience of the individual members informed how they wanted to conduct the research. I felt this to be entirely appropriate as there was a growing understanding in each member in relation to what it meant to them to be an adult with Asperger’s syndrome. The discussions, based on the data, generated new areas for exploration and gave a richer understanding of others with Asperger’s syndrome. I noted in Chapter Four that one of the benefits for service users of participatory research was a sense of identity and solidarity amongst disabled people (Beresford and Branfield, 2012). This was the first time all of the co-researchers had taken part in a group with other adults with Asperger’s syndrome where discussions of this nature had taken place.

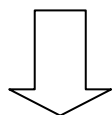
## **ii)      *Emergent themes***

The diagram below shows the three stages of the data analysis.

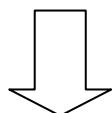
Data from questionnaires



Stage 1: Codes assigned to data



Stage 2: Codes reframed into 16 themes



### Stage 3: 3 main themes identified which summarised all 16 themes<sup>4</sup>

*Figure 3: Stages of data analysis*

In the first stage, all the data in the form of questionnaire responses was read by the group and codes were assigned to each response. Saldana (2013) discusses the use of 'coding filters', explaining that how a researcher perceives and interprets what is happening in the data depends on the filter they have over their 'researcher's analytic lens' (Saldana, 2013, p. 7). Saldana writes, 'multiple realities exist because we each perceive and interpret social life from different points of view' (Saldana, 2013, p. 8). As we were concerned to understand the data from the perspective of people with Asperger's syndrome, to use their 'filter' in the coding of the data was a crucial part of our method. My role was to facilitate the sessions where coding took place and to ask questions of the group to help them with the task. Emerson et al (2011) is cited by Saldana as advising using a general list of questions to consider when coding (Saldana, 2011, p. 21). Although I did not use an actual list of questions I had formulated in advance, I did use the technique indicated by Emerson as I asked two questions which I thought would encourage an understanding of the data:

- How would you summarise what the respondent is saying? and
- How do you understand what they are saying?

These questions asked two different things and this was indicative of what we were trying to achieve. They asked for an understanding of the data and a response to it. The first question was asked in order to encourage an understanding of how the respondent was answering the question and the second to encourage the 'filter' to be applied by the co-researchers. I tried to encourage a response from the group where they also used their own experience to make sense of the data. This strategy was consistent with a phenomenological approach but takes it a stage further.

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<sup>4</sup> The three themes will be identified and discussed in Chapter Seven

Phenomenology tries to provide a 'description of how things are experienced firsthand by those involved' (Denscombe, 2007, p. 76). The first question I asked was consistent with a phenomenological approach as the phenomenologist's initial task is to present the experiences of people in a way that is '*faithful to the original*' (Denscombe, 2007, p. 78). In phenomenological research, people are viewed as 'agents' who are able to interpret and make sense of their own experiences (Denscombe, 2007, pp. 78-79). Phenomenology allows for communities to see the world in a shared way (Denscombe, 2007) so it would seem appropriate for the co-researchers as adults with Asperger's syndrome to categorise the data from questionnaire respondents with Asperger's syndrome. However, the step of the co-researchers actually interpreting the data does mean a departure from a phenomenological approach. This is highlighted by my second question which concerned the understanding of the data. As Denscombe 2007, p. 81) explains:

A phenomenological approach not only encourages the researcher to provide a detailed description of experiences, it also advocates the need to do so with a minimum reliance on the researcher's own beliefs, expectations and predispositions about the phenomena under investigation.

Phenomenological research does not consider the possibility of participatory research. It does not usually allow for co-researchers who are from the same community as research participants and who can use their own experience of being a part of that community to make sense and interpret the data.

The next stage of the research concerned the focus groups and individual interviews, which, together with the conference will be the focus of the next chapter.

## Chapter Six

### Methodology II

This chapter will consider the focus groups and individual interviews as well as the conference. It concerns data production as well analysis. As stated at the outset of Chapter Five, the planning and project management of these stages contributes to the data set as does the data produced from the focus groups, individual interviews and the conference.

#### 1. Focus groups and individual interviews

##### a) Agreeing the next phase of the research

We discussed how we could gain greater depth to the three themes we had identified from the analysis of the questionnaire data. Despite the original reluctance of the co-researchers to gain data from face to face meetings with participants for the reasons discussed in the previous chapter, they were enthusiastic that the next phase of the research should involve focus groups and individual interviews. This decision was based on our discussions which involved a consideration of a number of factors. Firstly, focus groups seemed to be wholly appropriate for what we wanted to achieve. Two points that Denscombe (2007, p. 178) makes about focus groups are:

- There is a *focus* to the session, with the group discussion being based on an item or experience about which all participants have similar knowledge;
- Particular emphasis is placed on the *interaction within the group* as a means for eliciting information.

We were very clear about the focus of the sessions due to our previous data analysis. We also wanted participants to encourage each other to share their views, based on the common experience of having Asperger's syndrome. I was aware of the literature cited in the Literature Review about the ability of people with Asperger's syndrome to function well in groups (Attwood, 2007) and the co-researchers spoke of their own difficulties in groups other than our research group. However, we were undeterred as we had experienced a successful group in the research space we had co-created. We

wanted to show that the social model of disability could be applied to this research method, although a difference was that we would not know the participants in advance and so would be unable to check with them in advance of the session how to best work with them. Secondly, the responses to the questionnaire had varied in the level of detail and we wanted the opportunity to gain greater depth of responses. Thirdly, we wanted to explore our three themes further and believed focus groups to be an opportunity to do this. Fourthly, as we were much more confident in working together than we had been when we started to design the questionnaire, we thought that we could facilitate the focus groups in a way which built on what we had learnt from our working together. In other words, we wanted to co-create another metaphorical research space. This new research space would be an extension of the one we had already co-created. I will discuss below how we agreed to co-create this new space as we gave this full consideration after I discuss the design of the research tool we used.

#### **b) Design of the research tool**

We had started to plan the focus group phase of the research while we were still analysing the data from the questionnaires. We originally thought the questions would focus around identity and diagnosis and started to frame some questions in this vein. However, when we reached the point where we had identified three main themes in the data analysis of the questionnaires, we decided that these should form the basis of the questions for the next phase. The reason for this was that we felt that the three themes summarised all the findings from the questionnaire and also addressed what the co-researchers felt were important issues of identity and diagnosis (this will be discussed in Chapter Seven). We made notes on flipchart paper to assist in thinking of the questions we wanted to ask based on each of the three themes and recorded ideas in relation to each theme. We agreed on five questions for the first theme and three questions each for the second and third themes. As diagnosis fitted well into the first theme, we included questions about diagnosis under this heading. As had happened



previously, the co-researchers discussed their own experiences, this time in relation to the three themes.

### **c) Co-creating an autistic space for the focus groups**

The co-researchers and I were concerned that the experience of being in a focus group could be a very difficult one for some participants. I had not found any examples in the literature of a focus group involving adults with Asperger's syndrome so there were no models to follow. We had, however, successfully worked as a group and had co-created a research space which was enabling to all involved. Our aim was to apply what we had learnt to a focus group. We thought that giving a choice of how to participate was important just as we had offered different ways of completing the questionnaire to respondents. We decided to offer the choice of taking part in a focus group or an individual interview. MacLeod et al (2013) has shown that some people with Asperger's syndrome will choose face to face interviews when given a choice. However, this information was not available to us at the time. We had asked at the end of the questionnaires if participants were willing to take part in the next phase of the research and some respondents had said they were and had provided their contact details. We decided to offer two dates for focus groups, on different days, one in the afternoon and one in the evening and in different parts of the county we were based in. We also decided that individual interviews would be arranged directly with the participants who chose this.

Focus groups are usually facilitated by a 'moderator', who is the researcher (Denscombe, 2007). I did not want to assume that this role should be mine so we discussed who should facilitate the sessions. The co-researchers did not want to take on this role and were more than happy for me to do this. This was not surprising as the reluctance of the co-researchers to take on the role was consistent with both the literature (Attwood, 2007) and the roles they had played in our research up to this point. However, I did not want to make assumptions and if one of them had wanted to do this, we would have discussed how to support this. I was conscious that I was not

**the** researcher, but part of a team. We discussed what role the co-researchers wanted to have in the focus groups. One of the co-researchers did not want to be a part of this phase of the research as that individual felt very uncomfortable in group situations other than in our research group. The other two co-researchers were keen to take a part in the focus group sessions. We decided that the two co-researchers would have two roles to play. Firstly, they would be introduced as co-researchers. This was really important as it addressed the presentation of myself as the neuro-typical 'expert' researcher. I discussed in Chapter Four the potential for participatory research to replicate the power relationships that exist in society and we did not want this to happen in our focus groups. We would acknowledge in the sessions the role the co-researchers had in the whole research process. Secondly, they would be participants. We decided this for a number of reasons. We were worried that participants might feel uncomfortable and so be slow to contribute to the discussion. We agreed that if this happened, I could ask one of the co-researchers for a response, to start the discussion going. The co-researchers were also very keen to be participants as they were excited about the possibility of talking to other adults with Asperger's syndrome in relation to the three themes. They wanted to be a part of the discussion. According to Denscombe (2007), the interactions in focus groups help the researcher to understand the 'reasoning behind the views and opinions that are expressed by group members' (Denscombe, 2007. p. 179). The way we planned to conduct the focus groups adds another level to this. The co-researchers, who were co-producers of the research, were to become participants. This meant that they were a part of the interactions to help understand the opinions of the focus group participants. Focus groups provide opportunities for rich data to be produced as ideas can be shared and developed within the group. We felt that the contribution of the co-researchers would add extra depth to the discussions. Greener (2011) discusses the potential for focus groups:

The construction of meaning in focus groups is achieved, provided the facilitator can play a relatively minor role, by the participants themselves, a move that

addresses power imbalances between the researcher and the researched as well as giving the maximum space for shared meanings to emerge (Greener, 2011, p. 78).

Our decision that the co-researchers should also be participants was rooted in our understanding of the dichotomy of power being between people with Asperger's syndrome and neuro-typical people rather than between the researcher and the 'researched'. This was based on how people with Asperger's syndrome experience society as expressed by the co-researchers and in the concept of 'Other' as discussed in the Literature Review.

Interpretative phenomenological analysis is concerned with how phenomena appear, and as Smith et al (2009, p. 28) explain, 'the analyst is implicated in facilitating and making sense of this appearance'. We planned to use the co-researchers initially to contribute to the appearance of the phenomena and later to be a part of the analysis of these same phenomena. In our co-creation of another autistic space for the focus groups, we merged the roles of researcher and participant. However, this was consistent with our aim to understand the experience of adults with Asperger's syndrome. Denscombe (2009) has identified the identity of the person asking the questions as affecting the data. We thought the fact that the co-researchers were also present would ameliorate any negative influence that my identity as a neuro-typical moderator might have and potentially inhibit or constrain the discussion. In practice this worked very well. The co-researchers contributed to the discussion as part of conversations within the focus group. They said less than other participants as they wanted to hear what others had to say. They certainly did not lead the discussion as others were very forthcoming in their responses.

The role of moderator was allocated to me as I am neuro-typical and so should not contribute to the discussion, apart from as a facilitator. I was also more comfortable with this role than the co-researchers. My contribution to the focus groups was to be as outlined by Denscombe (2009, pp. 179-180):

- Creating a comfortable atmosphere for the discussion;
- Introducing the stimulus;
- Keeping the discussion on track, focusing around the topic;
- Encouraging participation from all members;
- Ensuring there is no abuse or intimidation.

We had learnt from our experience of the piloting of the questionnaire that not everyone with Asperger's syndrome necessarily understood questions that made sense to the co-researchers. As we did not pilot the focus group questions in the same way, we also wrote 'prompt' questions to help if the questions were not clear enough or if the response was not detailed enough (Appendix 6). These were not actually used as the participants in the focus group stage gave full answers to the original questions and did not need any clarification.

#### **d) Generating data from focus groups and individual interviews**

Having written our questions for the focus groups, we contacted everyone who had completed a questionnaire who had indicated they were willing to take part in the next stage of the research. We also contacted other groups of adults with Asperger's syndrome and other services for adults with Asperger's syndrome. We composed a letter and an invitation to take part in the focus groups or individual interviews (we offered a choice) from the group and these were sent out (Appendix 7). Ethical approval had to be gained for this stage of the research as the University ethics committee wanted to see the questions that we were planning to ask.

Having obtained ethical approval, we held two focus groups and three individual interviews. None of the contacts from the questionnaire stage of the research accepted our invitation to be a part of this next stage of the research. All of the participants at the focus group stage were from contacts I made with local services who supported adults with Asperger's syndrome. This meant that the research had more participants overall. It also meant that the new participants had not contributed

to the original data so might have very different views to the original participants. This offered a good test for our three themes as we would see if they were meaningful to other people with Asperger's syndrome by the way they answered the questions. As already stated, I had not read of any research regarding using focus groups for people with Asperger's syndrome or autism so I was unsure how successful this stage would be. We decided as a group to try this method of data gathering but to give participants a choice of being part of the two focus groups we planned or being interviewed individually. We also gave the participants who were interviewed individually a choice of venues, although in all cases they chose to be interviewed in their own homes. Two people indicated that they would like to be interviewed individually. One of these indicated that they would like someone else with Asperger's syndrome to attend, so a co-researcher attended this interview, which took place in the person's home. The other interview took place in the residential setting where the participant lived and I met with him alone as he stated that he did not want anyone else present.

We audio-recorded the sessions and one of the co-researchers volunteered to transcribe them as she said she would like to gain experience in this area. We did not know in advance who was going to attend the focus groups and left it to participants to attend if they wanted to. This was another aspect of co-creating an autistic space as requiring participants to agree to attend could have been anxiety provoking for them. At the first focus group, in addition to one co-researcher and myself (the second co-researcher was unable to attend), only one participant attended. The participant was an Asian woman. This session became practically an individual interview by default although the co-researcher decided to contribute, even though there was only one other participant. At the second focus group, in addition to myself and two of the co-researchers, five adults with Asperger's syndrome attended. Of the five participants, four were white men and one was an Asian male. The participants were accompanied by four people between them in a support capacity, three paid carers and one relative. I made it clear at the outset that the session was to hear the views of the adults with

Asperger's syndrome and asked that the carers and relative refrain from commenting. This was adhered to by all and they sat by the participants they were accompanying but did not contribute themselves. The purpose of a focus group is to produce a shared meaning (Greener, 2011) and we did not want this meaning to be influenced by the views of neuro-typical people.

I facilitated the focus group by asking the questions we had agreed as a group and kept the session running to time as well as explaining if anything was unclear. The co-researchers and I attempted to make the focus group an autistic space in a number of ways. Firstly, as explained, we gave people the choice to take part in a group or to be interviewed if they preferred. Secondly, we prepared an information sheet (Appendix 8) to make the participants aware of the way the session would be conducted in advance so that there was an element of predictability about it. This was made available to the participants we knew were going to attend and those that turned up on the day were given the opportunity to read it and have it explained prior to the session. Thirdly, we encouraged participants to come with someone to support them if they wanted to. Fourthly, I went through the consent form (Appendix 9) and the information sheet at the beginning of the session to ensure that everyone understood what we were going to do before we started and answered any questions. Fifthly, I asked everyone to introduce themselves and to state whether they were there as a person with Asperger's syndrome or were there to support someone. Sixthly, we agreed when we would start and finish and when we would have a break and I ensured that we did this, again making the session as predictable as we could.

With all the individual interviews and focus groups I stuck to the questions we had agreed in advance. There was one exception to this and that was a participant who lived in residential accommodation and had requested in advance that I come to interview him alone. When I arrived it became apparent to me that the participant probably had autism rather than Asperger's syndrome as I had been informed. I started to ask him the questions as agreed but his first response was 'I don't get that

one', indicating that he had significant trouble in understanding and responding to the question. In order to interview him, I deviated considerably from the questions and conducted the interview more as a conversation based on his responses to me. Data from this conversation was included in the research alongside the data from the other interviews and the focus group.

The co-researchers and I developed this way of conducting the focus groups by thinking about how best to work with other adults with Asperger's syndrome. This resulted in some aspects of the process of the focus group being unusual but with the outcome conforming to what the literature says about desired outcomes. Kreuger and Cassey (2009, p. 202) write that validity in focus groups is measured by the quality of the information and how accurately it reflects how the participants felt. The authors recommend pilot testing the questions and listening to participants to understand what conditions need to be created for 'free and open sharing'. Although we piloted the questionnaire, we did not pilot the focus group questions. We used the experience of the co-researchers and what we had learnt from the questionnaire to develop our focus group questions and how we were to conduct the session. We used the themes from the questionnaire data analysis to inform the questions, thus aligning them with what the questionnaire respondents had said. We used the experience of the co-researchers to develop our focus group method as described above. As Greener (2011, p. 77) states, focus groups have the advantage that they can achieve 'a more naturalistic environment than interviews in which the interviewer plays a much reduced role'. My role in the focus group was to facilitate the best conditions for the participants to be able to speak freely and this was achieved by the way the session was managed. The literature does not anticipate the role of co-researchers in focus groups so it does not address what their role should be. In our focus group, the co-researchers contributed to the meaning in a way that I did not. Greener (2011, p. 78) writes:

The construction of meaning in focus groups is achieved, provided the interviewer can play a relatively minor role, by the participants themselves, a move that addresses

power imbalances between the researcher and the researched as well as giving the maximum space for shared meaning to emerge.

Construction of meaning was achieved exactly by this separation of roles that I and the co-researchers played. The distinction was made between myself as the facilitator, the other neuro-typical people who attended as carers and the co-researchers and the other participants. It was the adults with Asperger’s syndrome who had a voice and who constructed the meaning in our session, not the neuro-typical people. We made the focus group session ‘culturally sensitive’, a quality that Smith (2009, p. 119) attributes as an advantage of focus groups. We used the session to examine the way in which individuals with Asperger’s syndrome ‘collectively make sense of a phenomenon and construct meaning around it’ (Bryman, 2008, p. 476).

#### e) Analysis of the focus group data

Before discussing the data analysis of this phase of the research, I will demonstrate it diagrammatically (see below):

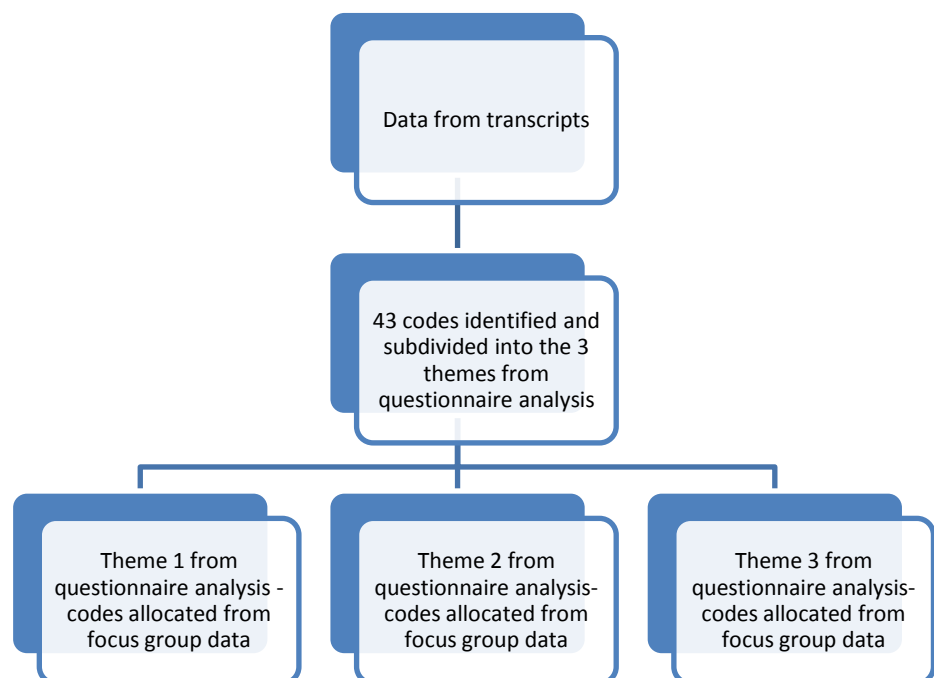


Figure 4: Data analysis from focus groups and individual interviews



When all the transcripts were complete, the co-researchers and I met again to analyse the new data. We discussed how we were going to conduct this phase. I was not sure whether the same technique developed for the questionnaires was the best method for this phase. However, we decided to go through the same process as with the questionnaires and read the transcripts as a group. We did this as this method enabled us to work together as a group and allowed us to discuss the data in a very thorough manner, as we discussed every line of data as a group.

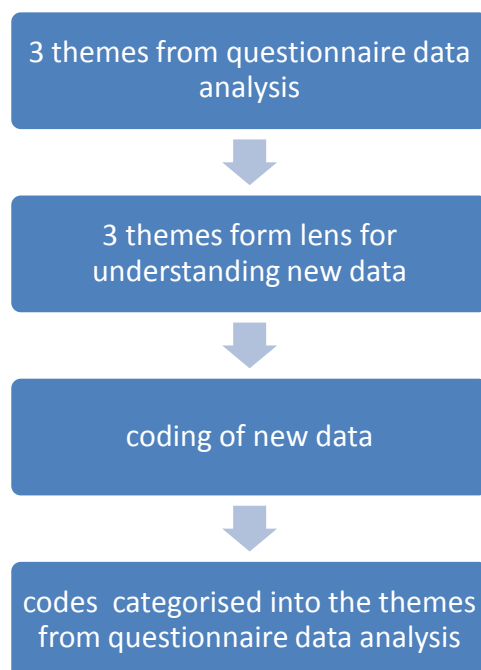
We also had found this method to be successful with the questionnaire data. Data analysis was new to the co-researchers. We had however found a way to analyse it together and adopting this method again gave predictability to our work which was important to the co-researchers. We wanted to continue to co-create an enabling research space and making our working methods predictable to the co-researchers was an important part of this. As in the questionnaire data analysis, we read together all the data, concentrating first on the individual interviews. We allocated codes as we read the data and gave each code a number and a title. The codes were new ones. We did not use the codes from the earlier stage of the research. As in the questionnaire data analysis, we looked for what the data had in common. (Although we did not adopt a grounded theory approach, a consideration of the stages in grounded theory does help to consider how we analysed the data.) The way we allocated codes is referred to in grounded theory as *open coding* (Denscombe, 2007, p. 98). The next stage of data coding, referred to as *axial coding* is where the researcher then looks for relationships within the data. This then progresses to *selective coding* where attention is paid to the core components of the data (Denscombe, 2007, p. 98). As Denscombe explains, the purpose of these stages is to 'arrive at *concepts* that help to explain the phenomena-basic ideas that encapsulate the way that the categories relate to each other in a single notation' (Denscombe, 2007, p. 98).

These concepts then form the cornerstone for theory generation (Denscombe, 2007, p. 98). This method in grounded theory is referred to as the 'constant comparative

method' as new codes are checked out against existing codes, leading to a refining of the codes (Denscombe, 2007, p. 99). Instead of looking for relationships within the data as in axial coding, we related the codes to the three themes we had identified in the questionnaire data analysis. We thought that we already had three themes that explained the phenomena, given that the phenomena in this context are the experiences of people with Asperger's syndrome living in a neuro-typical world. The purpose of this stage of the research was to interrogate further the three themes. However, the method we adopted had broadly the same aim as the three stages described in grounded theory. We wanted to continue to 'arrive at concepts that help to explain the phenomena' (Denscombe, 2007, p. 98). We wanted to look for relationships within the data. Whereas in grounded theory the new themes are 'checked out' against existing themes, we wanted to do more than this. We wanted to see how the new codes fitted into the existing three themes and see what new insights the new codes added to the themes and indeed how they deepened our understanding of the themes.

The analysis was influenced by the previous stage of the research in two ways. Firstly, the questions were based on the three themes, so the data from the focus group stage unsurprisingly accorded with the three themes. Secondly, the way we identified the codes in the focus group stage was heavily influenced by the thematic analysis of the previous stage. We used the three themes as a lens through which to understand the new data. We were looking for a deepening of the three themes rather than new themes to emerge. This method differs from grounded theory in that we were not looking for new themes to emerge from the data, but instead were looking for confirmation and strengthening of the themes we had already established. We then allocated the codes from the data analysis of the questionnaires to appropriate themes. We did this by considering each code and discussing what it meant and how it

fitted into the three themes<sup>5</sup>. We found that it was possible to allocate all our codes under our three main themes. We had not decided beforehand that no new themes would emerge but they did not do so. We identified 43 codes from the data. The influence of the three themes on the process of data analysis is represented diagrammatically below:



*Figure 5: Influence of three themes on coding of data from focus group stage of research*

The three themes from the questionnaire stage will be discussed in the Chapter Seven. However, an important point should be made here to provide context to the discussion. The group thought that when considered together, the three themes gave a way of understanding the experience of people with Asperger's syndrome and offered a model for providing support. In other words, we had been concerned with theory formation (again, this will be discussed further in next chapter).

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<sup>5</sup> Had we been unable to see how any codes fitted with the three main themes, we were going to discuss them to see what new insights these could give. However, we were able to categorise all the codes under the three themes.

## **2. Findings dissemination and more data production**

We were concerned that the co-researchers should have the opportunity to be involved in the dissemination of the research findings prior to my publishing and disseminating any results. We had co-created a research space in which a new way of understanding the support that people with Asperger's syndrome need was developed. This had been possible due to the way knowledge was produced. It was produced using the expertise and experience of the co-researchers and through them analysing and making sense of the data from other adults with Asperger's syndrome. I was mindful of the importance placed in the literature of the participants being involved in presenting and disseminating the findings (Tew et al, 2006). We wanted to work together to ascertain the best way of disseminating the results of our research. The co-researchers chose to do two things, firstly to hold a conference and secondly to have their own website.

### **a) The conference**

The generation of theory from the first stage of the research had an impact on all that followed. As explained above, the second stage of the research was based on it, from design to analysis. The theory had caused much excitement in our research group, from all the co-researchers (and myself). We wanted to tell others about it as we thought it contained important ideas for people with Asperger's syndrome and all who support them. The motivation of the co-researchers was to improve the lives of other people with Asperger's syndrome and having been part of this research and formulated theory which is potentially very beneficial to other people, the co-researchers were very motivated to be a part of the dissemination. In Chapter Four I used the following as a heading: 'A participatory space is where service users can feel personal gain and influence services and achieve positive changes' (p. 129). I viewed the dissemination of our results as part of our metaphorical research space. It was just as important to ensure this last phase of our research was in line with the principles of participatory research as the preceding parts. We wanted to disseminate our findings and tell people about our theory as we wanted services and support to improve. We

also wanted to present a clear message about how the research had been conducted and what people with Asperger's syndrome can achieve, providing they are supported in an enabling way. I have stated in the Literature Review that a participatory space that leads to change outside of itself results in service users feeling valued about the way they have exercised power (Dow, 2008; Fleming, 2012). It was the exercise of power that informed the way we planned and conducted the conference. (As I will reflect on this in Chapter Ten, we were successful in some ways and made mistakes in others in relation to this).

#### **b) Planning the conference**

We followed the same principles that we had used to co-create our research space and we worked together in a way that was enabling to the co-researchers in how we would run the conference. We planned the conference in great detail and together scripted the whole event. We rehearsed what we were going to say many times as well as considered the practical details such as when to stand up, how to work the roving microphone and when to pass it on to the next person. We also went to the venue to become familiar with it prior to the conference and practiced what everyone was going to say. The conference was a great success and we received a lot of very positive feedback. It was attended by over ninety people, including other people with Asperger's syndrome, family members and many professionals. The co-researchers felt very happy with the conference as they said that they had had the chance to show what they were capable of doing. They succeeded in portraying the needs of people with Asperger's syndrome in a different way and one not based on a deficit model. We used the three themes and theory developed from the first stage of the research to inform the conference design.

At the conference the co-researchers and I talked of our role in the research and explained how it had been conducted in all its aspects. As part of this we introduced our theory based on the three themes and each of the co-researchers talked about what this meant to them. Members of their families also spoke of their experience and how they viewed the research and our findings. We ended with case studies that we

had written together and which were also based on the three themes. We asked that groups consider the case studies in relation to our three themes and reflect on what insights our theory gave to the situations posed. The case studies were all based on experiences of the group members or situations they knew that other people with Asperger's syndrome had experienced. At the end of the conference, we asked that the attendees complete an evaluation of the event. The way we planned our conference meant that not only did we disseminate our findings, but more data was produced. The data was in the form of the script which we wrote for the conference, my reflective diary and evaluations of the feedback from participants at the conference.

#### **c) Group identity**

One very pleasing aspect of the conference planning was the obvious pride the co-researchers took in their identity as co-researchers and of our research group. They wanted to show that they were a part of the group. This included me as the co-researchers chose that all of the group members wear tee-shirts which identified us all as members of the Asperger's Consultation Group at the conference. One of the group members designed a logo for the group (Appendix 10) and printed it onto the tee-shirts that we wore.

#### **d) Website development**

We were very keen that the co-researchers be able to communicate with anyone who was interested in our research and have a platform from which they could tell people about it. We designed a website together ([aspergersconsultationgroup.org](http://aspergersconsultationgroup.org)), which we developed in the same way, that is, we discussed it as a group and agreed the layout, which photographs to use and the text for it as a group. This website is for the co-researchers as they want to continue meeting beyond the scope of this research. Two years after creating the website, the group decided to replace it with a blog (Asperger's Consultation Group, 2014a) a facebook page (Asperger's Consultation Group b, 2014) and a twitter account (Asperger's Consultation Group c, 2014). The co-researchers want more of an internet presence and think these will reach more people

with Asperger's syndrome. The content of the website will be discussed in Chapter Eight.

I have not yet given an account of the theory formation that I have alluded to in this chapter. This will now be considered in the following chapter alongside a presentation of the results.

## **Chapter Seven**

### **Findings I**

In this chapter, I will discuss the findings from the data analysis. It will also include a consideration of the process of the analysis. I will draw on my reflective diary and notes we made during meetings. The discussion will include how we arrived at the findings, especially how the co-researchers interpreted the data and made sense of it. I will comment on this process and how their experiences influenced the findings. In Chapter Eight, I will discuss further findings from the dissemination stage of the research, as this produced further data. I will first discuss the findings from the questionnaires and then the focus group and individual interview stage of the research in this chapter.

#### **1. Questionnaire data**

The questionnaire was divided up into sections, with each section given a title. I will discuss the data from each section under the same heading as in the questionnaire. Firstly, I will present the quantitative data.

##### **a) Section A 'About You'**

As described in the methodology chapter, we devised a questionnaire based on what the group thought were the areas of inquiry related to support where we judged there was a possibility of influence. The group did feel strongly about some other areas, not covered in the questionnaire, most notably the benefits system but thought this to be too ambitious an area to effect change. The details of how the questionnaire was formed and its constituent parts are also described in the methodology chapter. I have included the responses to the first part of the questionnaire below as this gives demographic details of the participants (the ethnic group column uses the term that respondents chose to categorise themselves):



<b>Participant</b>	<b>Gender</b>	<b>Age range</b>	<b>Ethnic group</b>
1	Male	40-49	White British
2	Female	18-29	British
3	Female	18-29	British
4	Male	30-39	British
5	Male	18-29	British
6	Female	18-29	Indian
7	Male	18-29	White British
8	Male	18-29	White British
9	Female	18-29	White British
10	Male	18-29	White British
11	Male	30-39	White British
12	Female	40-49	White British
13	Male	18-29	White British
14	Female	40-49	White British
15	Male	18-29	British
16	Female	18-29	White British
17	Female	18-29	White British
18	Female	18-29	British
19	Female	30-39	British Asian Indian

*Table 2: Demographic details of respondents to questionnaire*

Part A of the questionnaire asked for personal details as above. In addition it asked where people lived and with whom. The reason for this was that we felt that there

might be specific issues that respondents raised that related to their individual circumstances or identity. There was an almost even mix of gender, with nine males and ten females. Most of the respondents identified themselves as either white British or British, with two females identifying themselves as 'Indian' and 'British Asian Indian'. Thirteen of the respondents were in the 18-29 age group category, three in the 30-39 and three in the 40-49 category. Five lived with their parents, all in private accommodation, except one who lived with parents in a housing association or council property. One lived with their parents and a partner in a private property, two lived with a partner in private properties, four lived in shared accommodation, either residential or supported living, one lived with friends in a private property and six lived alone. Of the six who lived alone, two lived in 'supported living' so would be supported by paid support workers, the other four living in private property. Although we asked these questions as we thought there might be correlations between the data and participants' individual identities or circumstances, we did not actually use this information to analyse the data. The reason for this is that when we analysed the data, we thought that the themes we identified were applicable to all people with Asperger's syndrome as they were universal themes irrespective of other factors which might influence their lives. This will become clearer when the findings are discussed.

#### **b) Section B 'About you'**

Part B was concerned with diagnosis and all 19 respondents answered that they had a formal diagnosis of Asperger's syndrome. The group had chosen to use the word 'diagnosis' rather than 'assessment' as they felt this was a reflection of their experience. It could be argued that the insistence of the group on knowing about and using the term 'diagnosis' was at odds with the emphasis on the social model of disability. However, as Molloy and Vasil (2004) have written, diagnosis offers an explanation of what sets people with Asperger's syndrome apart. It enables them to make sense of their lives. This was clearly felt by the co-researchers and they were very clear that this was an important question to ask. The term 'diagnosis' is a medical one, but this seemed unavoidable when people are assessed within a medical context

and it was felt that this would be the term that all potential participants understood. I will discuss each further question below and identify and discuss the data that was produced in response.

Question B1: Have you got a formal diagnosis of Asperger's syndrome?

All replied 'yes' to this.

Question B2: How old were you when you were diagnosed?

Again, although we thought this an important question to ask, this information was not used in the data analysis. What is quite striking is that of the six respondents who were in either the 30-39 or the 40-49 age categories, four were adults at the point of diagnosis. It seems a possibility that the older adults who responded had a much more recent experience of diagnosis and this might account for their willingness to take part in the research. It is possible that they were adults who were still looking for answers about their own identities and experiences.

Question B3: What effect did diagnosis have on your access to services?

Six choices were offered for a response. It was clear from the data that diagnosis did have an effect on access to services, as five respondents selected the response that services increased as a result of diagnosis. Eleven respondents selected the response that they either were too young at the time of diagnosis to be able to comment or that they did not receive services prior to diagnosis. Only one respondent chose the response that indicated that services stayed the same after diagnosis.

Although, as Molloy and Vasil (2004) show, diagnosis is important as it often helps people with Asperger's syndrome make sense of their lives, the group felt that support was an important element in this and so we asked what support people had received in relation to their diagnosis (question four). We offered a choice of 'yes', 'no' or 'I was young so I can't remember'. Eight respondents could remember receiving support and eight indicated that they received no support at all. Those who did receive support

were asked to complete questions five to eight and those who did not receive support were asked to complete question nine.

Question B5: What kind of support was it and who gave it to you?

This was an open question with no set answers. All eight people who received support answered this question. Seven of these stated who gave the support and this included health professionals, a social worker, one to one support at school, a voluntary agency and a family centre. One respondent stated 'it helped me in a tribunal for Incapacity Benefit', although this respondent did not state who gave this support. A different respondent said that the support 'explained what Asperger's is as a disability' and this was support from a paediatrician. Another respondent wrote 'health and wellbeing' and this support was received from a social worker and psychologist.

Question B6: How helpful to you was this support?

The response choices were offered in a Likert scale ranging from 'very unhelpful' to 'very helpful'. Only one person thought the support they received was 'unhelpful' and this was in the form of support sessions at the respondent's school. Four thought the support had been 'helpful' and four thought it had been 'very helpful'. One of the four who responded that the support had been 'very helpful' had indicated in question four that they did not receive any support, so it is difficult to ascertain the meaning of their responses.

Question B7: Please state what it was about the support that made it unhelpful, if it did.

This was an open question. Only one person thought it was unhelpful and this was one to one support he received at school. He stated:

'Although it was an opportunity to talk to somebody about my Asperger's, I felt like we were going through the motions and that I never got any real help or advice'.

Question B8: Please state what it was about the support that made it helpful, if it did. Again, this was an open question. Of the seven responses, most referred to the benefits of having a diagnosis, rather than how the support related to the diagnosis actually helped them. They detailed practical benefits such as access to services. One respondent stated that the support:

...put it in layman's term for me. Looked back at childhood and it all fitted together. Explained to me why as a child I had behaved as I did e.g. had no friends at school.

This accords with Molloy and Vasil's (2004) writing on the importance of diagnosis. For another respondent, diagnosis and the support that they received in relation to it, held the key to understanding themselves as well as explaining their lack of friendships as a child.

We also asked two questions for those who had not received any support at the time they were diagnosed.

Question B9: Would you like to have had support?

Respondents were given a choice of answers from 'yes', 'no' or 'it was offered and I declined'. All eleven respondents to whom this applied answered the question. Nine indicated that they would have liked support and two stated that they would not.

Question B10: If you had no support but would have liked it, what kind of support would you have liked?

Responses were made by five out of the seven respondents to whom this was applicable. One respondent said that 'anything would have been helpful'. This respondent explained that she was diagnosed when she was 16-17 years old which was 'too old to be seen by specialist or teams for children but too young to be seen by

relevant teams for adults'. Another respondent started her response with the statement:

I'm not really sure, which is a part of the problem I suppose. It seems that if you struggle to identify and express exactly what support you need and from which services, nobody is prepared to support you much at all. This seems quite a flawed system to me, considering that communication problems are an inherent factor in autistic spectrum disorders.

The same respondent states:

People are either completely uninterested or offer very ineffectual, inappropriate help. Furthermore, there have been times when I have been promised that a phone call will be returned once further inquiries have been made on my behalf, and no one has bothered to get back in touch at all. Surely people working within these kind of services should have the awareness around autism to realise that they shouldn't make promises like these to someone who is likely to take them absolutely at their word and sit by the phone waiting for a call, only to be left feeling confused and disenfranchised?

This highlights a really important point about the understanding needed by professionals in supporting people with Asperger's syndrome. What might be very annoying to most people can be experienced much more intensely by people with Asperger's syndrome. The fact that many people with Asperger's syndrome take language literally does mean that they can feel confused when people do not do what they say. Of course, it is extremely poor practice to neglect to phone a service user back as promised, but professionals probably do not realise that a person with Asperger's syndrome might literally sit by the phone waiting.

Although I noted that most respondents linked the benefits of support with diagnosis to practical outcomes, such as increases in services, one respondent would have liked to have been given support to 'deal' with diagnosis in a way that 'was not linked to services'.

A different respondent identified that she did not receive any support in 'understanding my condition and managing it.' She wanted to 'be understood' by others as well as to understand her own 'condition'. She wanted to be able to make friends and be accepted in society.

The need for self understanding as well as the need to be understood by others can be seen in the data in this section. If diagnosis is the key for people with Asperger's syndrome to understand themselves, the data indicates that support is needed to use this key.

### **c) Section C 'Interacting with People'**

Section C of the questionnaire was concerned with 'interacting with people'.

Question C1: Do services help you relate to people?

Respondents were offered choices of response from 'not at all', 'they help a little', 'they help a lot' and 'I don't receive any services'. Four respondents said that services had not helped them relate to people at all, six said they 'helped a little' and eight said that they 'help a lot'. One person indicated that they 'did not receive services'. It is noteworthy that more than half of the respondents who received services said that they either did not help at all or only 'a little'.

Question C2: Are you receiving any services that are helping you relate to people? '

The options for the answer were 'yes' or 'no'. All respondents answered this question with eleven stating 'yes' and eight stating 'no'. We asked two similar questions in questions C1 and C2 as the first one concerned the principle of whether services helped them relate to other people and the second one was whether they were currently receiving any services which helped in this way. Three respondents who answered question C1 as 'they help a little' indicated in question C2 that they were not receiving any services that helped them in this way.

Question C3: If you stated 'yes', please state which services helped you relate to people.

Ten out of the eleven respondents who this question applied to completed this section. The respondents referred to a voluntary organisation that helped 'when making phone calls', befriending, social workers, support received in supported living, support in a residential unit, day services and a women's group.

Question C4: Please describe what they have done that has helped you relate to people.

This was an open question. Five respondents detailed being given opportunities to socialise and two wrote of being given confidence to interact with people through being supported at the times of the interactions. Three respondents specifically referred to 'understanding'. One respondent stated that her social worker 'understands me and she has helped me by explaining people's behaviour and how to cope with difficult situations'. One respondent wrote simply 'understand me'. Another person wrote 'talking about my experiences with people helps me to put my social interactions in perspective and helps my understanding of other people and also of myself.' Highlighted here is the need to be understood in order to be supported effectively. The need for self understanding is also evidenced.

Question C5: Please describe what improvements to services could be made to help you relate to people.

This was an open question which ten respondents answered. Two indicated that services were either 'doing their best' or were helping them. One respondent was not sure what else could be done and one commented that an improvement would be to offer some support 'in the first place'. The actual suggestions for improvements were in relation to being offered support in how to cope with stressful situations caused by not understanding the behaviour of other people, practical workshops to help people with Asperger's syndrome to be able to communicate with others as well as the



opportunity to interact in groups. As in the responses to how services have helped, the responses indicate that understanding of others is important, either to aid positive interaction or to understand why interactions might not have been successful.

#### **d) Section D 'Dealing with the Outside world'**

Section D asked questions about 'dealing with the outside world'. The wording of this title had been the subject of much debate amongst the group and had been explored at the piloting of the questionnaire. It was felt that 'the outside world' was the most appropriate way to describe people's experiences beyond their personal relationships and within their families. An additional explanation was added to question D1: 'for example places where you might work, study, socialise or shop' to make the meaning clearer.

Question D1: Do services help you deal with the outside world, for example places where you might work, socialise or shop?

Respondents were offered a choice of responses from 'not at all', 'they help a little', 'they help a lot' and 'I don't receive services'. Only three respondents stated that they did not receive services, with one respondent not answering this question. Out of the fifteen who did receive services, three thought that they did not help at all in dealing with the outside world, five thought they 'helped a little' and seven thought they 'helped a lot'.

Question D2: Please describe how services help you deal with the outside world, if they do.

The responses were mainly concerned with practical assistance such as making phone calls, taking the respondent out, helping socialise, and helping with work, shopping and college as well as feeling more confident and 'accepting who I am today'.

Responses that addressed the 'how' of the question detailed evaluating 'my social interactions after they have happened', helping the respondent to 'communicate and

behave with neuro-typical people' and help to understand 'how society accepts things and how people should be'.

Question D3: What improvements could be made to services to help you deal with the outside world?

This was an open question. Nine respondents answered. Three of these expressed satisfaction with services in this regard, one replied that they would like to know about any services that helped with this as they did not receive any, two said that they managed without services helping and two respondents gave suggestions for improvements. One respondent highlighted that services are not responsive to emergencies and she would like services to help with anticipating situations. Another respondent would like help with practical skills, including 'social skills and behaving in public' and 'how to make and keep long term friends and possibly partner also'. As above, support in anticipating interactions or social situations is indicated as a need which is not met by services for these individuals.

#### **e) Section E 'Access to Work'**

This section concentrated on support to access work and how helpful or not support was in this area.

Question E1: Have you had support in finding work?

Respondents were offered 'yes' or 'no' as options. Twelve respondents stated they had received no support in finding work, six said that they had and one respondent did not answer.

Question E2: If you answered yes, who provided this support?

Of the six people who this applied to, five responded. Three cited voluntary organisations, two cited local authority services (although one commented that the service they referred to had been cut so no longer existed) and one also referred to a family member.

Question E3: Please describe what was unhelpful about the support, if anything  
Only one person answered and stated 'nothing that was unhelpful'.

Question E4: Please describe what was helpful about the support, if anything.

Five respondents answered this question. These were mainly concerned with actually locating work or voluntary opportunities, offering practical support and gaining 'reassurance' and 'setting realistic goals'. There were no suggestions to what else could have been helpful from support.

Question E5: If there was anything missing from your support which would have been helpful you, what was it?

Eight people responded to this question. Two respondents stated that they would like help in either looking for educational opportunities or looking for work. Two responses were concerned with the attitudes of employers. One respondent expressed concern that an employer would discriminate against him because he has Asperger's syndrome. Another respondent related previous experience where employers had not understood her 'difficulties' and so expressed the need for a job that 'worked alongside my Asperger's' and an advocate to discuss with the potential employer what she could and could not do. A lack of understanding on the part of employers of people with Asperger's syndrome is indicated rather than a lack of understanding of the workplace on the part of the person with Asperger's syndrome. This respondent clearly feels that employers have had unrealistic expectations of her due to them not understanding her. She says that employers have 'prioritised my qualifications over my difficulties and this makes me ill' and concludes 'I need assurance this would not happen again'.

Question E6: If you didn't have support to find work, what support would you have liked to help you find work?

Nine respondents gave answers. Eight of these had indicated in question E1 that they had not received support, although one respondent stated that he had received support but still answered this question. He answered 'none', which may mean that the question did not apply to him or that he did not want any further support. Of the other seven who answered, one respondent wanted help in finding 'an education', one did not really answer the question, but stated that they had asked for support and this request had been turned down, one stated that they were unable to work due to 'mental health issues' and one replied that they would like assurance that an employer would not use their Asperger's syndrome 'against me'. Of the remaining three, one was unsure what support he would want as he did not know what was available and one wanted someone to advocate on their behalf with an employer in relation to what they could and could not do and one wanted support looking for a job and training. One respondent also stated that she had received support in writing a CV and interviewing. However, for her, the support she needed was in finding a job which 'worked alongside my Asperger's'.

#### **f) Section F 'Work'**

Section F was concerned with the experience of being in work.

Question F1: What types of work have you done?

A choice of responses was offered: 'self-employed', 'voluntary supported', 'voluntary unsupported', 'paid supported', 'paid unsupported' and 'I have never worked'. Three respondents stated that they had never worked. Of the remaining sixteen, one was self employed, four had voluntary supported work, six had voluntary unsupported, four had paid supported and two had paid unsupported work. Two respondents gave answers which were not listed as an option. One said that they had done voluntary work but did not indicate whether it was supported or unsupported and one respondent had been supported in work by the college they attended. Some had done more than one type of work.

Question F2: If you had support in work, was it helpful?

This gave a choice of responses from 'yes', 'no', or 'I have worked but have never had support in work'. Four respondents stated that they had worked but never received any support. Three respondents stated that the support was helpful and three stated that it was not. Two of the respondents who stated that the support had been unhelpful had done voluntary work. The third person responded to the previous question that they had only had unsupported work, so it is difficult to interpret these responses. The three respondents who said that their support was helpful had done voluntary work. There was some confusion between these two questions as already noted as some respondents contradicted themselves. Another example of this was one respondent who replied to question F1 that they had done 'paid supported work', to question F2 answered 'I have worked but have never had support in work'.

Question F3: If it was not helpful, please describe what was unhelpful about it

It was an open question but with the instruction to respond 'I have not received support' if this was the case. Two respondents replied as instructed with 'I have not received support'. One respondent stated that it made his 'illness worse'. It is not clear whether this respondent is referring to Asperger's syndrome or mental ill health. One respondent stated that his 'bosses' didn't like people coming into the workplace and one stated that the meetings were irregular and that there was a non understanding of tasks, but it is not clear whether this refers to the support or whether the respondent did not understand the tasks. For one respondent, the support was in relation to her job but 'I don't receive support whilst I'm working only around my job I do'. This is difficult to interpret as this respondent lives alone in private accommodation, so does not receive any support from services there as far as I can tell from her responses. She does attend a women's group so it is possible that she receives support from there in relation to her job. Another respondent highlights the difficulties she encounters with the support that she receives. She answered with 'the structure-the unregular meets to see how getting on, the non understanding of tasks'. For this respondent, the

support is not adequate and she does not understand what is required of her by her employers.

Question F4: If it was helpful, please describe what was helpful about it.

Question F4 instructed respondents to state 'I have worked but have not received support' when this was applicable. This was an open question. Six respondents answered this question. Two respondents answered that they had not received any support. For one respondent, what was helpful was having support in 'settling in' to a job with 'staff slowly withdrawing'. This respondent lived in a residential unit, so presumably the 'staff' were from this unit. For one respondent what was helpful was 'knowing that there is someone there if I need them', so it is the reassurance of having support if it is needed that was helpful to them. For another respondent, it was the support which enabled them to 'not get sacked' as it helped her 'deal with different kinds of people'. For one respondent, what was helpful was that it 'keeps me busy and out of the house'. These responses all demonstrate the difficulties that people with Asperger's syndrome experience in the workplace. These are due to employers not being flexible enough to allow them to be supported effectively or in relation to the uncertainties that interacting with other people present to them or in some cases, respondents receiving no support at all. Understanding is the common theme in relation to the support, either of a lack of understanding on the part of employers or of people with Asperger's syndrome not understanding other people or the task they are required to do.

#### **g) Section G 'Other information'**

Section G was included to ensure that if there was an issue that the questionnaire had not addressed that the respondent deemed important, then they were given the opportunity to address it. It left the respondent free to write what they liked. One respondent identified that she had been misdiagnosed a number of times. One respondent stated that he did not receive any support until he went to university. Another respondent wanted Asperger's syndrome to be recognised as a disability and

this would in turn lead, in his opinion, to access to blue badges and bus passes. One respondent identified that she had not been made aware of any services since her diagnosis and had only benefitted from diagnosis as she understood herself better. For another respondent it was important that other people learn about Asperger's syndrome so that they can be better understood. One respondent stated that she was regarded as 'too mild' to have access to services but she needed support in maintaining her relationship with her partner and in running a household. She concludes:

I am not in denial about my Asperger's. I know what it is and how it effects me but I don't think any of the above is out of bounds if I could find some help. I am entitled to live as close to 'normal' life as I can manage and with help I can achieve this. I just don't know where this help is.

Another respondent stated that more help was needed for families to understand people with Asperger's syndrome. She also stated that society needs a better awareness of Asperger's syndrome.

Having described the data from the questionnaire responses I now want to build on the discussion in the methodology chapter (Chapter Five) concerning the data analysis.

## **2. Questionnaire data analysis**

### **a) From coding to themes**

As described in the methodology chapter, the data from the questionnaires was analysed by myself and the co-researchers by looking at every response and attributing codes to them. We gave codes to the qualitative data given in response to open questions. Although we did look at the quantitative data, we did not attribute codes to this. This initial analysis gave rise to between 5 and 19 codes for the data resulting from each question. The resulting codes were many and rather descriptive. However, this was consistent with coding techniques as coding is not analysis, but is a crucial

aspect of analysis as it 'leads to the idea, and from the idea to all data pertaining to that idea' (Richards and Morse quoted in Saldana, 2013, p. 8). We wanted to progress from a long list of codes with nothing linking them to finding themes. We discussed how to find themes amongst the codes. One of the co-researchers suggested two criteria:

1. Objective criteria-how many times a topic crops up in the answers.
2. Subjective criteria-what seems important to the group

The classification of 'objective' and 'subjective' criteria was suggested by the same co-researcher. This was an interesting suggestion. The second criteria not only made explicit the role of the co-researchers in interpreting the data, it also implied much more. The suggestion implies that the co-researchers would be able to use their own experience to filter the data in terms of its importance. I had encouraged the co-researchers to think of themselves as 'experts' and they saw themselves in this role. They thought they had the expertise to make judgements about the data in terms of what was important or not. Although we did not define how the co-researchers would determine this, reflecting on the discussions it is clear to me that they regarded data as more significant when it concurred with their own experiences, as the discussion below will show.<sup>6</sup> We chose not to count merely the amount of times a code appeared in favour of deciding how important each code was. We decided to start to theme the codes and then to make a decision about what were the most important. We took each code in turn and discussed what we thought it meant to the respondent. This inevitably used the co-researchers' experience of similar situations to understand the data. The codes from Section B question 10 serve as an illustration of this. The list below shows the codes we assigned to the data with the theme we then attributed to it in parenthesis:

- 1: Help with identifying and expressing needs (me understanding me)
- 2: No flexibility in services (others understanding me)
- 3: Bespoke support (others understanding me)
4. Anything because nothing was available (others understanding me)

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<sup>6</sup> This approach was in line with the methodology. The data was interpreted through the experience or lens of the co-researchers (Nind, 2014).



5. Support is required but can't identify what it is (me understanding me)
6. Talking therapy (me understanding me)
7. Diagnosis specific support (me understanding me)
8. Understanding of Aspergers (others understanding me)
9. Managing/coping with Aspergers (me understanding me)
10. Being understood (others understanding me)
11. Support with independent living skills (practical skills)
12. Support with social situations (communication skills)
13. Managing behaviour in public (communication skills)

We went through all the codes for every answer and from that exercise drew up a list of 16 themes:

1. Me understanding me
2. Practical skills
3. Communication skills
4. Individualized support
5. You understanding me
6. 1 to 1 support
7. Support from being in a group
8. Volunteering opportunities
9. Encouragement to be social
10. Me understanding others
11. More contact with people with Aspergers
12. Practical support
13. Emotional support
14. Opportunity to be social
15. Better promotion of services
16. More responsive services

We discussed the links between these themes and decided that three of them actually summarised all the others. These three themes which captured the others above were:

1. Me understanding me
2. Me understanding you
3. You understanding me

The co-researchers wanted to refine the wording of these slightly, as they were not happy with our original use of the word 'you'. They wanted the wording to reflect the perspective of a person with Asperger's syndrome. They wanted the focus to be on the person with Asperger's syndrome rather than other people. The use of the word 'you' the co-researchers felt was too personal and did not reflect the significance of the misunderstanding which they experience as this took place so widely. We changed the wording of these to:

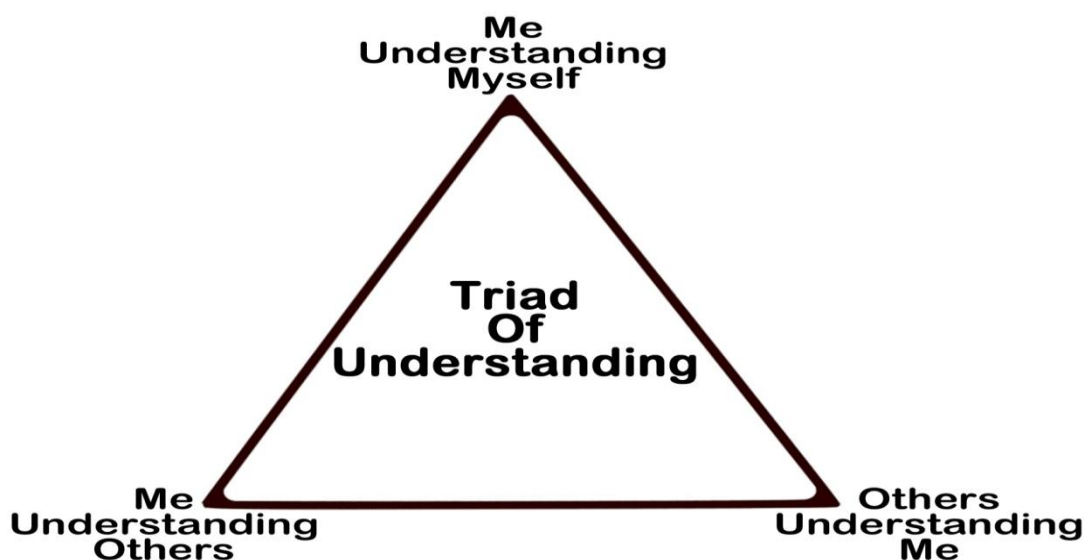
1. Me understanding myself
2. Me understanding others
3. Others understanding me

The change of wording was an important decision as it made the person with Asperger's syndrome central to the themes. The use of the word 'others' here is not in the Foucaudian sense, but simply refers to neuro-typical people generally.

As we discussed these three themes further, the links to the other themes became more apparent. For example, 'communication skills' were greatly enhanced when someone with Asperger's syndrome understands other people. 'Emotional support' often takes the form of trying to understand self or others. 'Individualised support' and 'one to one support' the group thought could be in the form of helping with understanding in the three areas. Many of the other themes the group decided were actually just opportunities to gain understanding in these three areas, for example 'volunteering opportunities', and 'opportunities to be social'. The co-researchers were more competent than me at linking the 16 themes with the three we had prioritised. To make sure that all the themes could be summarised by these three themes, we looked back at the data where we had assigned codes and then assigned the code to a

particular theme. One example of this was in the coding of an answer to a question which asked respondents to describe what improvements could be made to services to help the respondents relate to people. One respondent had answered 'Far less bureaucracy' and we had coded this as 'practical support'. One of the co-researchers explained that this was actually about 'Others understanding me'. It was because society was organised by neuro-typical people that bureaucracy had resulted which people with Asperger's syndrome found difficult to cope with i.e. they were misunderstood by 'others' and did not themselves understand others.

Through further discussion it was agreed that these three themes summarised what the group felt people with Asperger's syndrome wanted from support services and that they themselves felt that they needed. Based on our discussions of the medical and social models of disability and our discussion of the usual way in which people with Asperger's syndrome were understood, it became clear to me that what we were seeing in the data and what the group was voicing was a radically different way of understanding Asperger's syndrome. I suggested that we put the three themes in a diagram, using a triangle to represent and link them. I drew what this would look like on flipchart paper:



*Figure 6: The Triad of Understanding*

It was evident that this triad would represent a very different way of understanding the needs of people with Asperger's syndrome. I was very familiar with the triad of impairment (Wing, 1991), which is based on a deficit model of understanding autism, as is clear from its name. I realised that this research was presenting the possibility of challenging this model. I thought the idea of using the same language as Wing i.e. using the term 'triad' was an attractive one. I explained this to the co-researchers and they were enthusiastic about this idea. We decided to call this diagram 'The Triad of Understanding'. This raised the possibility of replacing the deficit based model of the triad of impairment with a new one of the Triad of Understanding. This new model emphasises the responsibility of both neuro-typical people and people with Asperger's syndrome in developing meaningful communication. This contrasts markedly with the deficit model where the onus for change is focused on the individual with Asperger's syndrome alone.

We discussed the diagram further and the co-researchers agreed that when all three elements of the new triad exist i.e. when understanding is in place in all three of these areas, situations go well for people with Asperger's syndrome. One co-researcher pointed out that the reverse is often true in the experience of adults with Asperger's syndrome, so I drew another triad on flipchart paper:



*Figure 7: The Triad of Misunderstanding*

We decided to call this the 'Triad of Misunderstanding'. This was an important moment for the group as these two triads influenced everything that followed. The co-researchers felt that these demonstrated what they all needed to have in place to succeed in a variety of situations and in different relationships, as well as in society generally. As described in the methodology chapters, the following stages of the research were all based on these triads. The significance of these triads will be explored in the next chapter as they have the potential to be very important for people with Asperger's syndrome and neuro-typical people alike. They represent a significant contribution to knowledge in relation to Asperger's syndrome, how people with Asperger's syndrome should be supported and how there is a mutual responsibility on behalf of neuro-typical people and people with Asperger's syndrome to understand each other. Although this discussion will be deferred to the next chapter, I now want to consider this research and the subsequent production of theory.

#### **b) Theory Production**

We did not set out to produce theory. We had set out to ascertain what support people with Asperger's syndrome want in order to live their lives. It did not occur to

myself or the co-researchers that we were engaged in theory production at the time. Mason (2002, p. 182) cites Coffey and Atkinson's suggestion that researchers should 'concentrate more on how we 'make and use' ideas, than upon constructing theory *per se*'. Coffey and Atkinson (1996, p. 156) write: 'What are needed are the generation and imaginative use of ideas that guide our exploration and interpretation of the social world'. It was the motivation of the co-researchers and myself to 'make and use' ideas that led to the production of theory. This will also be explored further in the Chapter Eight. For now, it is important to note that the production of the theory was unanticipated, but was perhaps predictable due to the underpinning of the research on the social model of disability.

### **3. Focus groups and individual interviews**

We based the questions for the focus groups and individual interviews on the triads of understanding and misunderstanding and the three themes which they are based on. The questions for this phase of the research were based on the group's discussion of the Triad of Understanding. The questions addressed each element of the triad in turn and asked how important each area was. As many discussions with the co-researchers focused around diagnosis, we wanted to ask questions about people's experience of diagnosis as this seemed to be an important area. We devised additional questions which linked the understanding of self (me understanding myself) to diagnosis and how it helped in an understanding of self. We asked how the participant felt about having Asperger's syndrome as the co-researchers thought this was important to self understanding. We also asked what had helped in understanding other people and what had helped other people understand the participant. The purpose of this phase of the research was to gather more data to give a richer understanding of the three themes.

The co-researchers and I developed a way of conducting the focus groups by thinking about how best to work with adults with Asperger's syndrome. This resulted in some aspects of the process of the focus group being unusual, as will be explored below. Kreuger and Cassey (2009, p. 202) write that validity in focus groups is measured by

the quality of the information and how accurately it reflects how the participants felt. They recommend pilot testing the questions and listening to participants to understand what conditions need to be created for 'free and open sharing'. Although we piloted the questionnaire, we did not pilot the focus group questions. We used the experience of the co-researchers and what we had learnt from the questionnaire to develop our focus group questions as well as how we planned to conduct the session. The themes from the questionnaire data analysis informed the questions, thus aligning them with what the questionnaire respondents had said. We used the experience of the co-researchers to develop our focus group method as described above. As Greener (2011, p. 77) states, focus groups have the advantage that they can achieve 'a more naturalistic environment than interviews in which the interviewer plays a much reduced role'. My role in the focus group was to facilitate the best conditions for the participants to be able to speak freely and this was achieved by the way the session was managed. The literature does not anticipate the role of co-researchers in focus groups so it does not address what their role should be. In our focus group, the co-researchers contributed to the meaning in a way that I did not. Greener (2011, p. 78) writes:

The construction of meaning in focus groups is achieved, provided the interviewer can play a relatively minor role, by the participants themselves, a move that addresses power imbalances between the researcher and the researched as well as giving the maximum space for shared meaning to emerge.

Construction of meaning was achieved exactly by this separation of roles that I and the co-researchers played. The distinction was made between myself as the facilitator, the other neuro-typical people who attended as carers and the co-researchers and the other participants. It was the adults with Asperger's syndrome who had a voice and who constructed the meaning in our session, not the neuro-typical people. The co-researchers and I made the focus group session 'culturally sensitive', a quality that Smith (2009, p. 119) attributes as an advantage of focus groups. We used the session

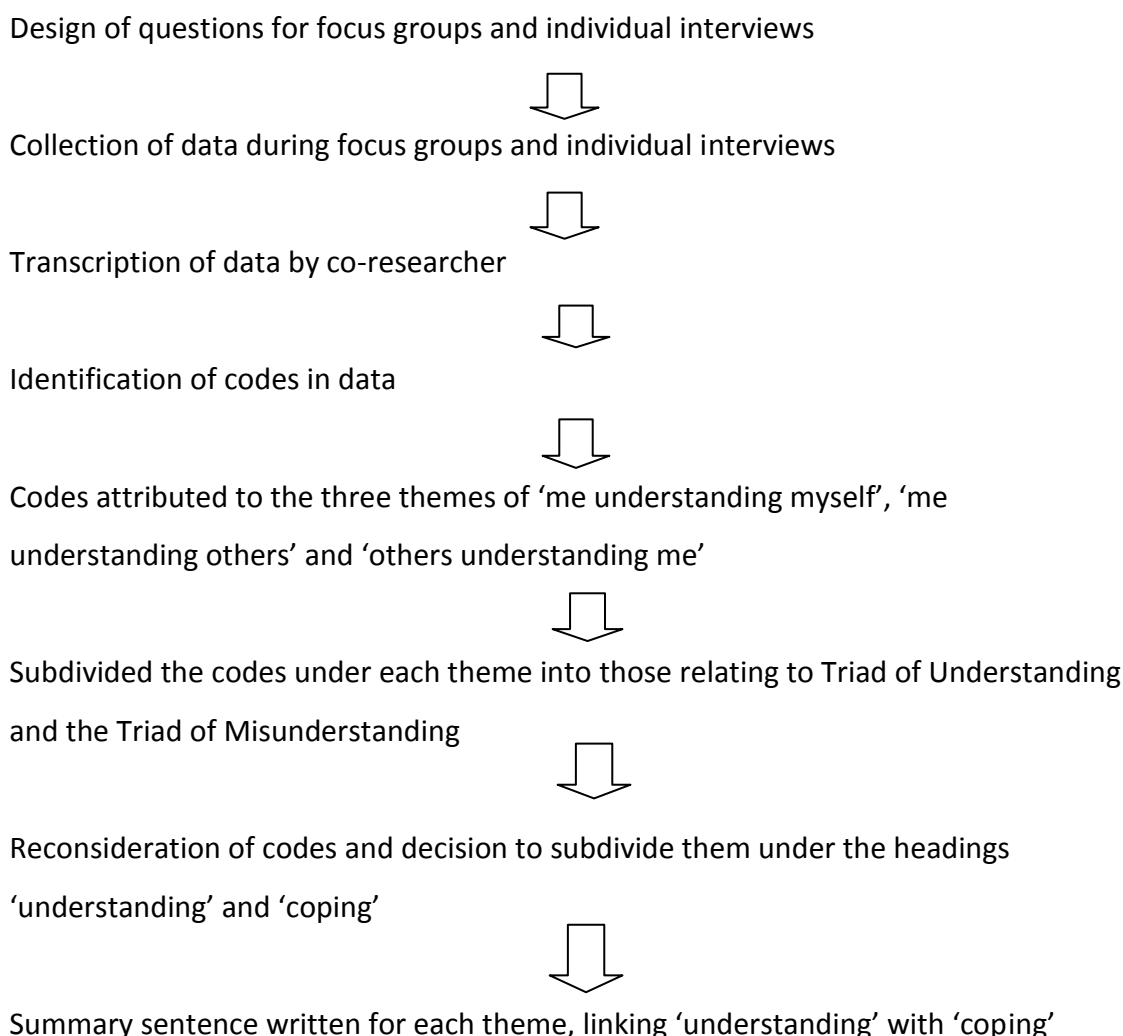
to examine the way in which individuals with Asperger's syndrome 'collectively make sense of a phenomenon and construct meaning around it' (Bryman, 2008, p. 476).

I discussed the questionnaire completions above and the different role that I played, dependent on whether they were self-completed or completed with my support. I used Cicourel's (1964) framework for considering meaning in three categories. I reflected that there could have been some difference in understanding based on Cicourel's third category of meaning: the importance of the domain of a topic. As the co-researchers and I conducted the focus groups together, the possibility of my different understanding of the importance of the topic having being at variance with the participants was addressed. While my role was typical of the usual role of a facilitator as described in the literature, the role of the co-researchers was distinct from mine. They were at the same time the 'inquirers' and the 'inquired' about. Their experience shaped the focus group questions so they were familiar with the intended meaning of the questions. They also used their experience to respond with the other participants to the questions. Their experience was shared, alongside that of the other participants and meaning was shaped through their discussions. This meaning was to be interpreted later in the data analysis, again using the experience of the co-researchers.

The importance of utilising group discussions and therefore multiple perspectives rather than just individual contributions to focus groups is highlighted by Tompkins and Eatough (2010, p. 248). It is through these different perspectives that discoveries may be made. According to Tompkins and Eatough (2010, p. 248), it is when participants interact and debate with other people that they become aware of their own implicit thoughts or opinions. The co-researchers had already had the opportunity to discuss with each other how they experienced the neuro-typical world. The focus groups gave the opportunity for other people with Asperger's syndrome to participate in a discussion that included the co-researchers and the participants' reflections were added to those of the co-researchers. It was a consideration of experience that the focus groups produced.



This stage of the research will be discussed below. It can be represented diagrammatically:



*Figure 8: Stages of focus groups and individual interviews*

We read all of the transcripts as a group and kept a list of the codes that the group thought summarised what each participant was saying. We identified forty seven codes, with five additional 'sub-codes' (Appendix 11). We devised sub-codes on occasions when new codes seemed to be very closely related to existing codes, but had a slightly different meaning or in one or two cases, a very different meaning but related to the same issue. One example of this is code 29 and sub-code 29A. Code 29

was 'I do want to be seen as disabled'; whereas code 29A was 'I do not want to be seen as disabled'. The coding of this phase was different to the coding of the questionnaire phase as we had a lot more data to consider. We often assigned one code to quite a large section of the transcripts whereas at other times, we would assign a number of codes to a short section. Once we had coded all the data and had our list of codes, we used the three themes from the Triad of Understanding as headings and attributed all the codes under them, according to where we thought they fitted. We later subdivided the codes under each of the three main themes into those that were appropriate to the Triad of Understanding and those that were appropriate to the Triad of Misunderstanding (Appendix 12).

I will summarise below how the data was understood to relate to each of the three themes from the two triads. I will also discuss the codes that we did not attribute to the themes in the triads of understanding and misunderstanding. These themes were all concerned with 'identity' and I shall consider this data after I have considered the data in relation to the triads.

This section concerning the Triad of Understanding is in two parts. In the first part I show how the data from the focus groups and individual interviews accorded with the three themes of the Triad of Understanding and in the second one I will discuss how we understood the data in relation to the three themes. I will use quotations from the transcripts which illustrate the points I am making. I will show that the data demonstrated a clear need for understanding in all areas of the Triad of Understanding.

**a) The Triad of Understanding-what the data says**

**i) Me understanding myself**

The first question was: 'How important is it to you that you understand yourself?' This does appear to be a rather leading question and so it may be unsurprising that the participants all stated that it was either 'important' or 'very important'. However, it

has to be borne in mind that people with Asperger's syndrome can be very 'direct' (Attwood, 2007) and respond well to a very direct approach. The co-researchers had thought that a very direct approach was appropriate to use in the questions. However, most participants went on to expand on their answers, indicating that self understanding was important to them as the following exchange between three participants in the focus group shows:

Participant 1: I think to me it is important that I know myself and my needs as a person

Participant 2: Yeah for me it's very, very important to understand myself

Participant 3: I think it's very important to understand yourself and then that way you get a close picture of who you actually are

All of the respondents responded in a similar way, indicating that it is important to the adults with Asperger's syndrome that took part that they understand themselves. The next question asked if the participants thought they did understand themselves. All indicated that they understood themselves only partially at best. As one participant stated: 'Sometimes I do, sometimes I don't'. When asked to explain this statement, she stated:

Sometimes, like I said the times when I don't understand myself, because if I act in a certain way or say a certain thing and I don't realise I'm saying it or doing it...erm... you know...I'm out of control then but some of the times I do know.

Another participant stated: 'I don't fully understand myself' and this was agreed with by all the other participants in the focus group. In an individual interview, one participant replied that he did understand himself, although he did acknowledge that he had misunderstood himself in the past. In an individual interview, one participant stated:

Sometimes I get confused about who I am ...erm...About my condition, how it affects me and how, you know, how I act in a certain way or what's expected of me in society...I really don't know why I act in a certain way which I don't understand sometimes but I am trying to overcome it the majority of the time.

### **iii) Me understanding others**

The first question of this part of the focus groups was: 'How important is it to you that you understand others?' In the focus group, one participant expressed difficulty with understanding her parents and friends at times and acknowledged that she did not understand how other people think. Another focus group participant stated that other people think in a 'totally opposite' way from him and this makes other people difficult to understand. A different participant explained why he thought it is important to understand other people: 'so you know how to behave in society so that people accept you because if you behave irrationally in society people just push you away'.

When I asked a question about what happens when you misunderstand people, the discussion between the participants in the focus group offers an excellent insight into their experiences as a result of misunderstanding other people. Here is an exchange between Participants 2, 6 and 7:

Participant 2: You get confused as to why you can't understand the situation, to me it's very confusing, I can't actually understand you know, jokes or metaphors or sarcasm...I'll pretend and nod my head like a nodding donkey and go along with it.

Participant 6: Yeah I just laugh but I think why am I laughing? Because I don't get it but I do it to try and fit in

Participant 7: The thing is, I smile, I'm like underneath I feel guilt and sadness because I just cannot get it

Participant 6: Those are the worse times aren't they?

Participant 7: Yeah because you feel it's like a shared experience that you can't share

Participant 6: Because everyone is laughing at it and you don't get it

Participant 2: It's like you're on the outside looking in

This extract from the focus group illustrates the theme of 'me understanding others' or more precisely 'me misunderstanding others' very well indeed. Participant 2 at the end of the extract also uses a spatial metaphor to illustrate the feeling of being an outsider, a metaphor which I discussed in the Literature Review in relation to people with Asperger's syndrome.

#### **iv) Others understanding me**

I asked the question 'How important is it to you that other people understand you?' One participant in his individual interview said that other people do not understand him as 'I'm a weird person'. He stated that he could not tell if people understood him or not; he expected them to but was not 'bothered' if they did not. In the focus group, one participant described how having a diagnosis had changed his attitude in this regard:

I used to think it was very, very important that other people understand me but now having been diagnosed and understood my condition I don't actually really care that much if people understand me.

Another participant in the focus group responded that it is hard for him to tell if he is understood by others as he can't tell what other people are thinking. In an individual interview, a participant explained that she expects to be misunderstood by other people but said that it was a reliefuse anger to her when she is understood: 'It is a big relief for me knowing that they understand me because it means I don't have to go into erm into me explaining myself and my actions you know, all the time.'

I have established that the data from this stage of the research did accord with the findings from the questionnaire stage and that the three areas of the Triad of Understanding are all areas where people with Asperger's syndrome struggle. They struggle in these areas in the context of living in a world dominated by neuro-typical people and neuro-typical culture as the extract above illustrates in relation to the use of humour.

I will now examine how we made sense of the three themes of the Triad of Understanding.

#### **b) The Triad of Understanding-how we made sense of the data**

We found that not all the codes we had allocated to each of the three themes of 'me understanding myself', 'me understanding others' and 'others understanding myself' seemed to fit neatly into the two triads. We discussed the codes which did not seem to fit and the co-researchers recognised that these were all concerned with 'coping'. For the co-researchers, coping is a big part of their lives as they all have developed strategies to cope in living in a neuro-typical world which they find quite 'alien'. Through discussion of the codes and linking them to the experiences of the co-researchers, we sub-divided these codes again into 'coping' and 'understanding leads to coping' (Appendix 13). The latter is concerned with the role of understanding in all three areas of the Triad of Understanding and how this leads to the ability to 'cope'. Having attributed all our codes, we summarised each of the three themes of the two triads in one sentence which the co-researchers felt expressed the essence of how we had interpreted the codes. I will discuss the codes as we grouped them. Firstly those that seemed to fit neatly under the theme and I shall discuss these under the heading 'understanding'. Secondly, those that we thought were concerned with 'understanding leads to coping' I will discuss under a heading of the same wording, and the same for the codes which were concerned with 'coping', which I will consider last.

#### **i) Me understanding Myself**

- Understanding

The data indicates ways in which participants gained understanding. One of these was through diagnosis and the code which summarised this was 'Diagnosis is a relief as it enabled further understanding' (code 19). One participant in the focus group described the difference that diagnosis had made to him: 'having the diagnosis has actually helped me, almost by actually, I was like sleep walking through life, almost like in stand by'. The same participant comments: 'So almost like it's empowered you'. Another participant in the focus group reflected:

...suddenly I've had my diagnosis and now my brains I'm switched on or part of me is thinking yeah, I've got so much more possibilities so I'm a totally different person but my family thinks I'm the same old person.

Shared experiences with other people with Asperger's syndrome were thought to aid self understanding (code 21). One participant in the focus group had attended a support group set up for people with Asperger's syndrome and had found this beneficial in that she related to the experiences which were shared. However, she stated that 'people are different' and she did not relate to all the other people in the support group. For another participant in the focus group, it was the focus group that had provided the opportunity to meet other people with Asperger's syndrome and he found the experience validating.

Others found that self understanding was gained by somebody explaining events to them after they had happened (code 30). The 'other person' in all three cases where this code was assigned was a neuro-typical person. For a participant in an individual interview it was a fellow student at college and for two other participants it was family members. In all cases the neuro-typical person had tried to explain the behaviour of other neuro-typical people as the participants had either misunderstood or not understood it.

Some participants found that they gained a better understanding of themselves through 'individual research' (code 18). For one participant, it was the desire to learn more about Asperger's syndrome that was identified as being helpful as he thought this would help him understand himself further. Another participant had 'looked it up on my own' to help him with his self understanding.

There was only one participant whose data was allocated the code 'Your understanding of yourself relies on the willingness of others' (code 25A). This was the participant who had autism, not Asperger's syndrome. He was very dependent on the staff at the residential unit where he lived as he did not go into the community without them. He stated that 'staff' did not support him with understanding himself but thought that it would be beneficial if they did.

'Self acceptance' (code 1B) was allocated to the data of 2 participants from the focus group. This was in response to the question 'what do you feel about having Asperger's?' One respondent explained: 'There is nothing I can do about it, I've got it so you know it's just something you've got to deal with isn't it.' One participant in the focus group, during a conversation about what the participants felt about having Asperger's syndrome said:

People with Asperger's like to be liked just for who they really are and I think that's the biggest hurdle for me, that's my biggest hurdle is to be liked for who I am but knowing that I am slightly different or that my mind works differently.

For both these participants, self acceptance seemed difficult. Both were aware that they are 'different' and this seems to have affected their self acceptance.

One participant acknowledged that other health or mental health conditions could have an effect or as the code states 'influence behaviour' (code 45). This participant explained that he 'suffered from post-traumatic stress' and he struggled to know when his behaviour was the result of having Asperger's syndrome and not understanding



other people or whether it was the result of his post-traumatic stress. No other participant was given this coding.

The data and codes so far have been in relation to self understanding, how this is gained and also how it is linked to self acceptance. I now will consider the codes which were allocated to 'Understanding leads to coping'.

- Understanding leads to coping

Understanding of self was regarded as a learning process (code 2). One participant from the focus group sums up well the sentiments expressed by two other participants: 'I'm on a learning curve, of learning about myself at the minute, I don't know fully yet but I'm getting there slowly'. Participant 2 makes a statement which indicates how understanding leads to coping:

It's very important that I have a good understanding of myself and everything that goes off with myself as such erm so even if things have prevented me in the past I make sure that I can come to grips with everything, you know that kind of stops me from understanding. I can get over that quickly because it's very important that I continue to understand myself.

Some participants highlighted the need to understand the role they played in social situations (code 33). All participants whose data was attributed to this code indicated that they struggled to know how to respond to other people in social situations and gave examples of where they had 'got it wrong'. For two participants this was understanding other people's humour and knowing how to respond to it. For a different participant, it was in relation to listening to other people and not knowing when to interrupt. Another participant stated that he struggled to understand what to do in relation to when he saw a stranger in distress of some kind. He did not know whether to approach them or not. All of these participants linked their experiences with learning more about the social world and so learning how to behave. This knowledge helped to inform the behaviour of the participants. Code 9 is 'Conscious

effort to improve behaviour to be seen as acceptable and improve relationships'. One participant in the focus group stated that she used to have 'outbursts' when with other people, but she learnt to change her behaviour:

I've managed over the years and I've learnt to know that it isn't acceptable in society; people won't stand for it or people will get a bit, you know, they'll back away, they won't want to help you or be your friend or come near you if you don't act in this way, so I've learnt to, to take the other approach, which is to be calm.

Another participant said he had been told by his primary school teacher about personal space in relation to interacting with the other children. He commented: 'you've just got to play by the rules...to get what you want out of it.' One participant felt that she had to explain her behaviour to others (code 27). When asked 'what do you want other people to understand about you?' this participant responded: 'It is a big relief to me knowing that they understand me because it means I don't have to go into erm into explaining myself and my actions you know, all the time.' This was the only occasion when this code was used. However, other participants' data was attributed with the code 'Explaining myself to others relies on me understanding myself' (code 7). As one participant explained: 'When I do understand myself when I've acted a certain way I find it easier to explain to other people, neuro-typical people for example'.

- Coping

It is clear from the data in the examples above that self understanding does lead to coping. We also categorised some codes under 'coping' and this category highlights the strategies that people with Asperger's syndrome have learnt to employ. Code 20 ('coping strategies are important') highlighted the importance of coping strategies. In the focus group, one participant, when talking about not being neuro-typical,

expressed distress that she had Asperger's syndrome and stated: 'I'm trying to find coping strategies to get on in life to deal with this.'

In the focus group, one participant said that he could use anger to get a point across but another, participant 5, responded to this suggestion by stating: 'It might be learning ways of dealing with what's causing the anger, finding new techniques and other ways of working round problems.'

Another participant from the focus group thought he could use anger as a coping strategy to show how he felt whereas a different participant wanted to have a more strategic approach to actually understand what caused the anger and then develop 'techniques' to deal with that. One participant explained that he had experienced difficulty with knowing how much eye contact to give a person in social situations, which is a difficulty for some adults with Asperger's syndrome (Attwood, 2007). He had come to understand what the difficulty was and developed his own coping strategy: 'And don't stare also I've learnt when you're looking at someone, look at something above them or a picture or something like that and not always staring at someone.' Participants had learnt that they had to be more conscious of their behaviour than neuro-typical people (code 36) and this is linked in the data with self control. As one participant comments:

It can be that people with our condition at least speaking for myself, can be incredibly self controlled than people who have a let it hang out attitude. I think my policy has always been to be very, very controlled.

This point raised a discussion in the focus group, when another participant commented that in that regard 'I'm positively Victorian', which the co-researchers and I took to mean that he was very self controlled. Another participant reflected on what these two other participants had said and stated:

What we can't do is the balance ...We can be controlled or we can be completely the opposite but we can't get that control and be balanced and get it just right. I think that's the problem.

This indicates that even when adults with Asperger's do have coping strategies, sometimes these lead to problems. One participant had learnt to distance himself from other people as a result of the social difficulties he faces (code 38B). This was seen by the co-researchers as being another strategy to survive in the neuro-typical world, as it was one that they said they employed. This participant talked about the 'bubble' that he had created and in which he felt safe. He knew that he could 'break free' if he wanted.

Another strategy that one participant employs to help him cope was to avoid situations that he is not prepared for (code 43). A different participant explained what he does when he does not feel comfortable in a social situation: 'I'll pull away the horses and say no and I'll stay at home or you know, I'll watch TV instead'.

Another participant remained as 'self sufficient' as he can be. One participant had many negative experiences which resulted in him 'convincing myself from an early age that I was self sufficient.' He stated later on in the conversation in the focus group: 'at this particular junction in my life it's irrelevant whether I have friends of the opposite sex or the same sex but I don't have a desire for friendships, full stop.' The co-researchers viewed this as another coping strategy employed due to negative experiences in social situations.

- Summary statement

The sentence which the co-researchers wrote to sum up the link between the three parts of the theme of 'me understanding myself' is:

Information about Asperger's syndrome, other people with Asperger' syndrome and experience and explanations from those around me help me in

understanding myself. A complete picture of myself helps me to develop coping strategies that in turn help me deal with life.

## ii) **Me understanding Others**

- Understanding

Under the heading 'Understanding' we categorised codes that related to the participants' difficulty in understanding other people. Code 33: 'Understanding role in situation' was a code that we had also attributed to 'Me understanding myself' and has already been discussed. This code refers to situations where the participants did not understand their own role in situations and this was due to their difficulty in understanding others and other people's roles in social situations. Code 30: 'Somebody explaining what has happened' was also attributed to 'Me understanding myself' as well as attributed to this theme and so has also been discussed earlier. This also refers to social situations and involves the misunderstanding of self as well as other people. One of the very striking points which the data demonstrated was in relation to the conscious effort made by participants to understand the 'whole picture of how people feel' (code 42). One participant expressed the complexity of trying to understand other people and to know what they are thinking and he explained that he gets confused between the presentation of emotion in others and the language that they use:

I think there's a difference with understanding emotion and the language because I think you can sense when someone's upset but not necessarily always read the language that they are speaking so you might understand that someone is upset but not necessarily why they are upset.

- Understanding leads to coping

We did not attribute any codes to 'Understanding leads to coping' under this theme.

- Coping

Under the heading 'coping' we allocated code 9: 'Conscious effort to improve behaviour to be seen as acceptable and improve relationships' which was also attributed to 'Me understanding myself' so has been discussed earlier. The code was viewed by the co-researchers as referring to a strategy employed by the participants in order to cope with social situations. The effort to 'improve behaviour' was for the purpose of being more acceptable to other people and comes from understanding better neuro-typical people's expectations in relation to socially acceptable behaviour. We also categorised code 36 under 'coping'; that is 'Have to be more conscious of behaviour if got Asperger's syndrome'. This has also been discussed previously as it was also attributed to 'Me understanding myself'. This code was attributed here as the co-researchers thought being conscious of behaviour was required in order to develop the coping strategies, such as trying to 'improve' or change behaviour.

- Summary statement

The co-researchers wrote the following statement to summarise this theme:

It is important to understand other people's language and behaviours. It helps me to understand what my role is and I cope by adapting my behaviour to improve my relationships.

### iii) Others understanding me

- Understanding

Under the heading 'Understanding', we allocated codes which referred to the motivation of others to understand, the assistance of others in helping with understanding and the willingness of people with Asperger's syndrome to explain themselves to others. Participants thought that other people's understanding of them depended on their willingness to do so (code 25). One participant expressed his view that people should try to understand him, although he was not optimistic about this:

I feel people should at least try and ask me because if they've not heard of the condition before, most people don't really care. All they know is that you're in your own little world or your own little bubble and they basically leave you alone. That's how it is.

When referring to the way he struggled in social situations, one participant stated:

What I've always thought is that I struggle in social situations. I know I do, I always have done. I've got loads better at it but if people understood us then maybe we wouldn't have the problem.

Although this is not directly relating to the willingness of others to understand, the co-researchers wanted to categorise it with code 25. They thought it demonstrated a general unwillingness of neuro-typical people to understand people with Asperger's syndrome as this had been their experience. One participant in the focus group had experienced being misunderstood on numerous occasions and stated that 'all I can do is try to explain'. For him, this was not always successful and the co-researchers interpreted this as an unwillingness to understand on the part of neuro-typical people. We categorised code 25A: 'Your understanding of yourself relies on the willingness of others', which, as stated above was attributed to data from the participant who had autism. The co-researchers interpreted this code through their own experience. They saw clear links between the willingness of others to understand them and how they thought and felt about themselves. They used the Triad of Understanding to think about their own experiences and believed that it was often the attitude of neuro-typical people and their misunderstanding of them that led to low self esteem. We attributed code 30: 'Somebody explaining what has happened/what is happening can be helpful' to this theme as well as to the two other themes and so this has already been discussed. The co-researchers felt code 30A should also be attributed to this

theme: ‘Somebody explaining what has happened, to a non-autistic third person,’<sup>7</sup> can be helpful’. One participant from an individual interview suggested that as his parents understood him well, they could play a role when others misunderstood him as he stated ‘what I say is not always exactly what I mean’. His parents could in fact, act as an interpreter to other neuro-typical people. I asked the participant who I thought had autism rather than Asperger’s syndrome what would help neuro-typical people understand him and whether it would be preferable for him to try to explain himself or for other people to try to do it. He replied ‘most likely somebody else explaining to them.’ We also attributed code 33: ‘Understanding role in situation’ to this theme. For the co-researchers, this also related to neuro-typical people understanding them and the fact that they did not always know what role they should take in social situations. Some participants expressed a view which can be summarised by one participant who stated that it did not ‘matter if people don’t understand me, but I am happy to explain myself if they do’ (code 35). One participant in the focus group commented:

I used to think that it was very, very important that other people understand me but now, having been diagnosed and understood my condition I don’t actually care that much if people understand me.

In an individual interview, one participant expressed that he helps people to understand his behaviour if they ask him, but is not really ‘fussed if they kind of understand or not.’ What these two participants say could be interpreted at face value as not caring if they are understood or not. Another interpretation is that these participants have given up on being understood due to their experience of being misunderstood. The discussion with the co-researchers about this led to the interpretation that it was the continued misunderstanding of neuro-typical people and a medical model view of Asperger’s syndrome which led to such resignation.

- Understanding leads to coping

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<sup>7</sup> I have added punctuation to this code which we did not use at the time in order to convey our intended meaning. Without punctuation, the code’s meaning is ambiguous.



We categorised Code 6: 'Being able to explain behaviour to others and have that accepted helps me feel more in control' under this heading. The co-researchers were able to relate examples of when they had experience of this. The examples all concerned either family members or very close friends. Of course, for people to be able to explain their behaviour, they have to have an understanding of it themselves. The co-researchers felt that being given the opportunity to explain their behaviour to others gave them a sense of control and also led to being understood better.

- Coping

Under the heading 'Coping', we categorised two codes which have already been discussed:

- Code 7: 'Explaining myself to others relies on me understanding myself'
- Code 27: 'Having to explain behaviour all the time'.

The co-researchers felt these codes were relevant to coping strategies in relation to 'others understanding me'. One coping strategy which people with Asperger's syndrome employ in relation to situations where they need to be understood by others is to try to explain themselves. Code 7 indicates that this is only possible when the person with Asperger's syndrome has self understanding. Code 27 was allocated to some data from one participant where she expressed that she was being constantly misunderstood.

- Summary statement

The co-researchers wrote the following statement to summarise this theme:

It is important that others understand me. When people understand me, they can explain things to me and then I can cope a bit better. I can help people to understand me by explaining things from my perspective, which overall improves my relationships.

**c) The Triad of Misunderstanding**

Having discussed the data and the codes we allocated in relation to the three themes from the Triad of Understanding, I will now turn to the Triad of Misunderstanding. Some of the codes were also attributed to the Triad of Understanding, and I will indicate when this is the case.

The Triad of Misunderstanding was formed by reversing the three themes from the Triad of Understanding. The three 'themes' from it were not actually part of our coding from the questionnaire stage of the research. We wanted to see if it was possible to allocate our codes from the focus group stage to the three themes of the Triad of Misunderstanding. I will keep the structure of discussion the same, but refer to 'misunderstanding' instead of 'understanding', 'misunderstanding leads to not coping' instead of 'understanding leads to coping' and 'not coping' instead of 'coping'.

#### **h) Me misunderstanding myself**

- Misunderstanding

Under the theme 'me misunderstanding myself', we attributed one code that was also discussed under the Triad of Understanding and three new ones that were not so allocated. Code 12 was attributed to this theme: 'Lack of explanation from others affects your ability to understand yourself' as the co-researchers thought that other people played a role in the lack of self-understanding of people with Asperger's syndrome. One participant from the focus group relates how nobody helped her to understand herself, 'least of all my parents that didn't really want to discuss it or accept that there was something wrong with me'. Related to this is code 16: 'Others misunderstanding me can lead to bullying which leads to issues understanding myself'. One participant discussed how he was misunderstood at school by his peers because he worked hard. He states that he got bullied as a result of being thought to be 'too into my work'. We made a note when we read this: 'misunderstood by peers if quiet and misunderstood by teachers if angry'. This was from discussions of the co-researchers based on their experiences. They felt that however they presented at school they were disadvantaged. They were either bullied for getting on with their work or got into trouble with teachers if they showed their frustration at being

misunderstood. Both scenarios led to low self esteem, in the view of the co-researchers and so contributed to 'me misunderstanding myself'. Code 13: 'Minimal post diagnosis explanation' is attributed to the data from two participants from the focus group. It is worth noting in this regard that many of the participants were diagnosed when they were very young so may not have been able to remember what support they were given, if any. One participant stated that she was given a leaflet about Asperger's syndrome but was not supported in understanding it. Another participant agreed and stated that he was given no support and so 'had to look it up on my own'.

Code 18A: 'Individual research restricts what you think you can do' shows the risks that can accompany being left to find out about Asperger's syndrome without any support. One participant stated, 'I thought if you had Asperger's your mind reading is terrible and you can't do literature at a high level'. Later in the discussion he commented 'I've also read that people say your imagination's defective if you got Asperger's.' One participant thought that people with Asperger's syndrome did not look 'normal' and commented with surprise that one of the other participants in the focus group did look 'normal'. Another participant in the focus group referred to her belief that she cannot fit into society. The co-researchers discussion of this code was again centred on their own experience. One co-researcher in particular had read a lot of the literature about Asperger's syndrome and had stopped doing some activities as they seemed to be inconsistent with what the literature said in relation to what people with Asperger's syndrome could do. The data does not seem to indicate that the participants necessarily had the same experience, but it does show that they had negative views of Asperger's syndrome based on what they had read. Some participants had their self understanding hindered by either misdiagnosis or late diagnosis (code 11). One participant from the focus group had previously been diagnosed with mental health needs. She explains: 'So I went through the grind mill of professionals and they didn't really help, they tried to help me but I was confused.'

A different participant from the focus group stated that if he had been diagnosed earlier, he might have been able to retain a job.

- Misunderstanding leads to not coping

Under the heading 'Misunderstanding leads to not coping' we attributed two codes:

- Code 14: 'Me not understanding myself creates conflict'.
- Code 5: 'When I cannot understand myself I feel 'out of control''.

Code 14 was attributed to one participant who explained that as he did not have a diagnosis until he was in his 40s he felt he had misunderstood himself and this had led to conflict in his employment. Another participant thought that his diagnosis made him 'an outsider'. The co-researchers thought that this was because he did not understand himself, but looking at the data again as I write this, I am not sure this is clear from the data. We also categorised what another participant said as code 14:

I got excluded from school three times and that was that. For being me. For being naughty. I was labelled as 'naughty' because I didn't understand anything.

A different participant had a similar experience and 'got taken out of class' for 'challenging behaviours' which she thought was caused by her not understanding herself. This lack of self understanding leads to the person with Asperger's syndrome feeling 'out of control' (code 5). One participant, in an individual interview stated that 'Autism can make you selfish some times' and 'I don't understand that some things can make me cross'. The co-researchers interpreted 'being selfish' and 'being cross' as a lack of control as this concurred with their experience.

- Not coping

We did not allocate any codes under this heading for this theme.

- Summary statement

The co-researchers summarised this theme in the following sentence:

Confusion arises when I misunderstand myself. I find it difficult to explain myself to others and they find it difficult to understand me. This confusion can lead to conflict and personal distress.

## **ii) Me misunderstanding others**

We only attributed two codes to this theme, one under the heading 'misunderstanding', code 31: 'I find it hard to understand other people' and one under the heading 'coping', code 38B: 'Distance yourself as a protective measure'. Code 38B was discussed previously as it was also allocated to 'Me understanding myself'. One participant stated:

I used to get confused when I tried to understand other people, how they, how their thought processes were because they, it was totally opposite to the way I was thinking so I thought, well, they won't understand me, I can't understand them.

Another participant stated that he does not understand the members of his own family. A different participant stated that he needs people to explain what other people say to him as he often does not understand why they say things. Another participant referred to his inability to understand the humour of neuro-typical people.

The co-researchers attributed code 38B to this theme as they thought that some of the participants were saying that they 'distanced' themselves from others to cope with the misunderstandings. This was a strategy that the co-researchers themselves employed.

- Summary statement

The co-researchers wrote the following sentence to summarise this theme:

When you find it hard to understand others, you find it hard to cope.

## **iii) Others misunderstanding me**

- Misunderstanding

Under the heading 'misunderstanding', we attributed two codes which had already been attributed to other themes and four new ones. Code 12: 'Lack of explanation from others affects your ability to understand yourself' and code 16: 'Others misunderstanding me can lead to bullying which leads to issues understanding myself' are the codes attributed to other themes so have already been discussed. Code 12 was attributed to this theme as the co-researchers felt that if other people did not understand the person with Asperger's syndrome, they would be unable to offer explanations or insights which would help with self understanding. Code 16 has an obvious link with this theme as a lack of understanding can lead to bullying. The other codes allocated in relation to 'misunderstanding' are concerned with different aspects of misunderstanding. Code 10: 'When you most need someone to understand you, you are least able to explain yourself' is evidenced well by one participant:

...when I'm in a fluster and, you know, in, kind of in, in an unpleasant mood then the last thing I can do or want to do is, is to explain my actions.

One participant from the focus group explained that if someone does not understand him and reacts badly to him, he is unable to explain himself, whereas if they react calmly and ask him for an explanation, he is able to explain himself. The co-researchers could relate to this and thought that this factor exacerbated misunderstandings further. Code 17: 'Me not understanding others can also lead to conflict' was attributed to this theme as the co-researchers felt that it was their misunderstanding of others which contributed to being misunderstood in turn. One participant explained the importance of understanding other people:

I also think it is important that you understand other people so you know how to behave in society so that people accept you because if you behave irrationally in society people would just push you away.

One participant gave a very good example of not understanding other people and what can happen as a result:

Somebody was upset and crying and erm and I kept asking them 'What's wrong? What's wrong?' And that was making it worse instead of comforting them or giving them time alone ....it got them winded up and they didn't like that and finally somebody moved me away.

It is interesting that the co-researchers wanted to attribute code 17 to this theme as the data does seem to be about 'me misunderstanding others' rather than 'others misunderstanding me'. The reason for this, as above, is that the co-researchers felt that the misunderstanding of others leads to a misunderstanding of themselves in return. In the example above, the participant did not understand the needs of the person who was upset or interpret any reactions to her as a cue to leave the person alone. She had empathy for the person, but did not know how to act to help. The co-researchers related this to their own experience and felt that situations such as this lead to being misunderstood by others. Some participants did not expect to be understood by other people (code 26). One participant said that she 'sometimes' expects people to understand her and sometimes not. Another participant refers twice to not expecting to be understood by others. A different participant does not expect other people to understand him, but comments that they should at least try. Code 24: 'Even if you gain a good understanding of yourself, can you trust other people to have a good understanding of you?' is attributed to data where the participant shows a reluctance to let people know they have Asperger's syndrome. As one participant stated: 'You can have a label in private though, you can be diagnosed and have a label and not tell anyone. That still helps you understand yourself.' This statement was made in the focus group and another participant added that he perceived telling people of his diagnosis as a risk as this can lead to rejection. He reflects, 'you can...be dismissed'. A different participant voiced the opinion that other people are not always willing or able to adjust to a person with Asperger's syndrome. In response to this

comment, another participant said that he wanted people to 'accept me as I am' and sometimes to 'make allowances' for him. A different participant responded to this comment and reflected that no one makes any allowances for him and continues: 'Even my mother hasn't acknowledged that I have this condition.'

- Misunderstanding leads to not coping

Under the heading 'misunderstanding leads to not coping', we attributed code 15: 'Others not understanding me creates conflict.' One participant stated that she was labelled as having 'challenging behaviour' at college, which she stated she does not understand as she 'was quiet'. Another participant also stated that he felt misunderstood. The co-researchers felt that these instances influenced the participants' ability to cope as it contributed to low self esteem. They had found this to be true in their experience.

- Not coping

Under the heading 'not coping' we attributed code 22: 'Different and conflicting messages make you incapable of defining yourself which in turn affects other people's ability to understand you'. One participant tried to define Asperger's syndrome in terms of how messages pass through the brain. This participant also thought Asperger's syndrome is a 'mental health condition'. A different participant responded to this by saying that although there are lots of books about Asperger's syndrome, nobody can 'define it fully'. Another participant was very confused about what Asperger's syndrome is. Her confusion originates from the different types of services she has received, some coming under the auspices of 'mental health' and some 'disability'. She defined Asperger's syndrome as 'a brain thing'. The variety of views about what Asperger's syndrome is will be discussed further below in relation to identity. It seems evident that as people with Asperger's syndrome are confused themselves, it makes it very difficult for them to understand themselves and as the code states, 'which in turn affects other people's ability to understand you'.



- *Summary statement*

The co-researchers did not write a sentence to summarise this theme. I think this was an omission on our part, rather than having any significance.

There were fifteen further codes which we did not categorise under either of the triads of understanding or misunderstanding. These codes were all concerned with identity and it is to a consideration of this that I now turn.

#### **d) Identity**

There were 15 codes which were not attributed to the themes of the two triads and I shall consider these in turn. Code 32: 'There are two types of people: Neuro-typical and Asperger's' and this refers to data where participants showed a clear distinction between themselves and neuro-typical people. Two participants drew a distinction between themselves and neuro-typical people based on their difficulties in coping with social situations. One participant explained that she thought people with Asperger's syndrome and neuro-typical people 'see the world differently'. She said she had been told that they use different sides of the brain from each other. Two participants had an exchange in the focus group about why they attended. They agreed they were at the group because they have 'problems with the condition' and because they also have 'certain special talents in areas that other people haven't got'. For these two participants, the differences are both negative and positive but both are perceived by them as being deviations from the norm. A different participant expressed the difference between people with Asperger's syndrome and neuro-typical people: 'I actually like listening to Radio Four! You know that's almost like the people with Asperger's radio station I sometimes think!' He was previously talking about other people of his age who like to go out and get drunk and for him a key difference was that he liked to listen to information programmes rather than join in with his neuro-typical peers. Although the participants have different ways of understanding the differences between themselves and neuro-typical people, the data does show that

there is consistency in agreeing that there are 'two types of people', as this code indicates.

One participant distinguished between himself as an individual and as one with Asperger's syndrome. Code 3 is 'Separates understanding Asperger's and understanding myself'. This code is only attributed to one participant who wanted to understand 'what was Asperger's and what is you'. He saw his Asperger's syndrome as what presents him with difficulties as he said he wanted to know what Asperger's syndrome is and what is him so he can tell 'what you are capable of and what you're not'. A very similar code also makes the distinction between the individual and Asperger's syndrome: code 44: 'Asperger's is a part of the person, not the whole'. One participant stated that he wants people to know that 'although I have Asperger's, you know, that's just one aspect of my life and I've got many strings to my bow'. This same participant later in the focus group separated out what he calls 'personality traits' and Asperger's syndrome and says that people need to understand the personality traits belonging to individuals with Asperger's syndrome as well as their 'condition'. A different participant in the focus group, in a discussion about 'blaming' behaviour on Asperger's syndrome, states, 'Then the parent has to learn where the Asperger's starts and where being naughty begins.'

This participant clearly saw a distinction between behaviour which can be attributable to having Asperger's syndrome and that which cannot. Code 28 is: 'It's important to people with Asperger's that they are seen as individuals'. Three participants in the focus group discussed the importance of not being regarded just as a person with Asperger's syndrome, but instead being seen and accepted in terms of their individual personalities. This sentiment is clearly expressed by another participant who ends the exchange by saying: 'when it comes down to being yourself and trying to be something you're not, I would rather be accepted by five people for who I am than five hundred people for who I'm not'.

There are some negative aspects of having Asperger's syndrome which are expressed by the participants. One participant felt that 'diagnosis can hold you back' (code 39). Another participant reflected that he sometimes wished he hadn't 'found out' that he has Asperger's syndrome and instead had 'just got on with my life'. Others thought that having Asperger's syndrome meant that you are seen as an outsider, and they did not like this (code 38). One participant stated that he would rather be seen as 'eccentric' than given 'some kind of label as an outsider', which is how he views having Asperger's syndrome. He stated that he does not want to tell people he has Asperger's syndrome because then he is 'defined by negative stuff'. Another participant spoke of his reluctance to 'shout it from the rooftops' that he has Asperger's syndrome because he 'needs to figure out who is trustworthy'. When discussing this data, the co-researchers thought that people who are not 'trustworthy' are those that view people with Asperger's syndrome as 'outsiders'.

Participants also viewed some aspects of having Asperger's syndrome as positive. They thought that 'people with Asperger's are better in some areas' (code 37). One participant referred to 'gifts and abilities' that are a result of having Asperger's syndrome. He cited examples of famous people who he thought had Asperger's syndrome: 'it's not a surprise to me that people say that Mozart or Beethoven had Asperger's because when you have Asperger's you can be really, really creative and you know, you can be at the top.'

A different participant thought that his ability to analyse had enabled him to attain his English degree. Another participant referred to situations where people with Asperger's syndrome are 'as good if not better than other people'. He also referred to someone who said to him, 'can I have some of the condition please?' He explains that this is because 'there are aspects of this condition that give you strengths over other people'. One participant referred to his 'photographic memory' and his 'ability to concentrate on detailed tasks and take something apart' as positives that he had identified and which he thought were all part of having Asperger's syndrome. Code 40

is 'Asperger's brings out intellectual qualities', and there is an overlap here with code 37, which I have just discussed. One participant talked of having a 'sixth sense in some areas but in other areas it's like I don't have a clue'. The same participant also referred to having an advantage over other people in terms of his ability to understand and analyse information. Code 41: <sup>8</sup>'People with Asperger's expected to be clever but not able to do anything with it' refers to how people with Asperger's syndrome think their abilities are viewed by neuro-typical people. This is only allocated to one piece of data and that is a comment from a participant who said that people with 'mental health conditions or a learning disability' can be an inspiration in what they achieve. I do not think the code can be ascertained from this data. It was in the discussion between the co-researchers that it was seen in this light. They felt that it implied that the achievements of people with mental health conditions or a learning disability are celebrated but the achievements of people with Asperger's syndrome are not, because they are not thought to have any useful application. This was true of the experience of the co-researchers and may well have been also applicable to the participants, but is not stated as such. Only one participant expressed that he was proud 'of who I am', which the co-researchers coded as 'Proud of Asperger's identity' (code 47). However, it is slightly ambiguous whether this participant was referring to his achievements or his identity as a person with Asperger's syndrome.

Participants felt that a clear sense of identity was important to them. Code 8: 'Confusion surrounding identity hinders the understanding of myself' and its corollary, code 8A: 'Being clear about identity helps me understand myself' demonstrate this. Code 8 is attributed to the data from a participant who said that the literature is not clear about what constitutes Asperger's syndrome as it is not properly defined. A different participant stated that she gets confused about who she is as she does not understand her 'condition'. Code 8A is attributed to one participant's data who stated that understanding the positives about Asperger's syndrome has 'really helped me.'

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<sup>8</sup> Although this code is not grammatically correct, I have left it as we phrased it at the time.

Some participants acknowledged that 'the attitudes of people without Asperger's influences my sense of identity' (code 23). One participant described how neuro-typical people have said negative things to her about having Asperger's syndrome. It was only when she had talked to other people with Asperger's syndrome and saw 'how they get on in life', that she thought she could succeed too. She reflects, 'I shouldn't believe it'. The co-researchers attributed this code to some data from another participant, who said:

That's an Asperger's way of looking: the world in some respects is black and white all the time and what I've learnt is it's grey, you know, it's in the middle somewhere, it's never, you know, one thing or the other, it's always somewhere in the middle.

The co-researchers interpreted this as referring to two ways of understanding the world, the 'black and white' being that of people with Asperger's syndrome and the 'grey' that of neuro-typical people. One participant had been influenced in the way he understood the world, as he thought the neuro-typical way is the 'right' way. The co-researchers thought this had implications for his identity as he had come to believe that the way that people with Asperger's syndrome understand the world is not the 'right' way.

In discussions with the co-researchers, we had discussed whether people with Asperger's syndrome should be regarded as 'disabled' or not. There were opposing views on this expressed by the participants. Code 29 is 'I do not want to be seen as disabled' and code 29A is 'I do want to be seen as disabled'. Three participants expressed the view that Asperger's syndrome should not be viewed as a disability. One participant stated: 'I don't like thinking I have a disability because I don't in any way whatsoever. What I have is a condition'. Another participant took a similar view and thought that Asperger's syndrome is not a disability 'because I can still function'. However, a different participant stated: 'I thought it was defined as a disability. Your

autism Asperger's is defined by stuff you can't do'. For one participant, it was important that Asperger's syndrome is defined as a disability as his access to services depends, in his view, on being categorised as 'disabled'.

In the next chapter I will explore the final stage of the research, which was the conference. I will discuss how this stage demonstrates how the co-researchers chose to influence other contexts and also how they made sense of the research.

## **Chapter Eight**

### **Findings II**

#### **The significance of the triads: Making sense of experience**

In this chapter I will discuss the final stage of the research, the dissemination stage. The co-researchers chose to present our findings at a conference and via a website. Both of these are part of the data set as they contain reflections from the co-researchers on the process of the research and its findings. Additional data was produced at the conference in the form of recorded feedback. The previous chapter discussed how the co-researchers used their own experience to understand and interpret the data from the first two stages of the research. I will now discuss the conference and what the data from it says about how the co-researchers used their experience at it. This is in keeping with the first aim of this research:

- Use a participatory approach to explore how adults with Asperger's syndrome make sense of their experience of living in a neuro-typical world.

Equally the issues raised were in accord with the third aim of the research which was:

- Reflect on how the principles of participation be most usefully applied in other contexts so that adults with Asperger's syndrome are more able to reflect on their experiences and express what they need from services.

In relation to the third aim, there was learning from the process of doing the research, which I anticipated would have a wider application to other contexts and there was the findings of the research i.e. the creation of the triads, which was less anticipated. Both of these offer insights into how participation can be usefully applied in other contexts as in the third aim. I will show how we thought the triads of understanding and misunderstanding offer a framework for other adults with Asperger's syndrome to reflect on their experiences and express what they need from services. I will discuss how the co-researchers wanted to disseminate the findings and theory production of

the research to an audience which could influence services and provide support for adults with Asperger's syndrome. Both I and the co-researchers wanted to influence the future experience of other people with Asperger's syndrome. The experience of the co-researchers shaped the research at every stage as the diagram below demonstrates:

Research scope based on **experience** of co-researchers



Research tools designed to find out about *experience* of other adults with Asperger's syndrome



Data interpreted using the **experience** of the co-researchers



Theory formation, using **experience** of co-researchers



Research tool designed (based on theory) to ascertain the *experience* of other adults with Asperger's syndrome



Data interpreted using theory and **experience** of co-researchers



Dissemination of findings through conference and website. Co-researchers relate theory and findings to their own **experience**

Figure 9: The role of experience of the co-researchers.

(I have put the experience of the co-researchers in **bold** and the experiences of other adults with Asperger's syndrome in italics to highlight the role of each).



(This diagram illustrates how central the experience of the co-researchers was to the research. It is not concerned with my role, which is discussed in the discussion chapters).

### **Dissemination of the research**

The final stage of the research was the dissemination stage. We discussed how the group wanted to disseminate our findings and in particular the triads of understanding and misunderstanding that had been developed. As part of our commitment to continue to work in a way which was consistent with the ethos of this research, we wanted the group to present the findings prior to me doing so as an academic.

## **The Conference**

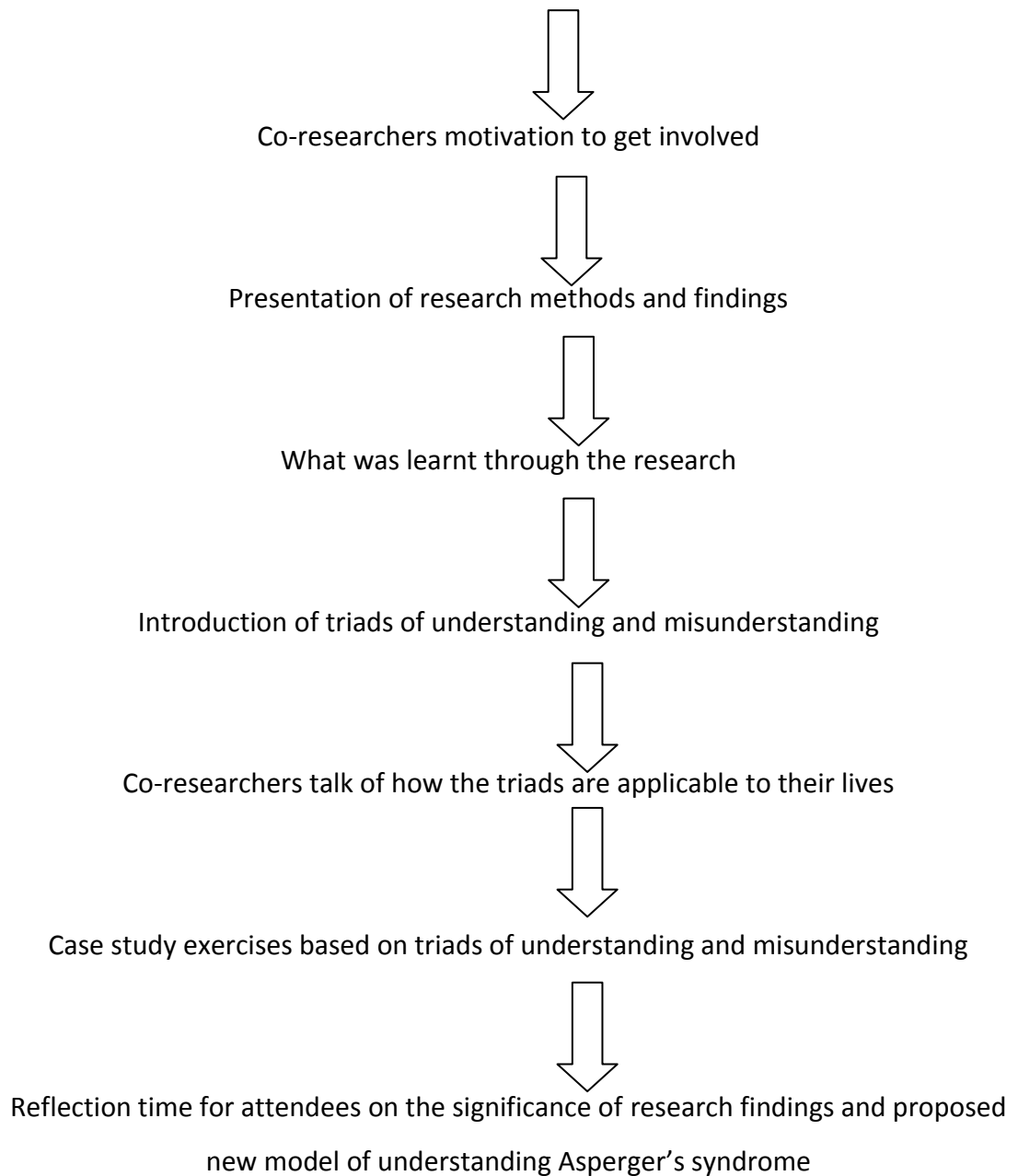
### **a) The co-researchers use of their own experience**

We decided to call the conference 'Reclaiming the triangle'. The aim of this was to make reference to the triad of impairment and to present an alternative perspective on Asperger's syndrome. The co-researchers were very enthusiastic at using the same geometric shape as is used to depict the triad of impairment (The National Autistic Society, 2012a) which for them symbolised what was said to be 'wrong' with them and make this the centre of the conference. This included making this central to our flyer (Appendix 14). As already mentioned, they also designed a logo for the group which was based on a triangular shape.

In order to help the attendees grasp the different way of understanding Asperger's syndrome that we were proposing, the conference was designed to help them understand what it is like to have Asperger's syndrome and to misunderstand and be misunderstood. The programme of the conference mirrors the way in which the co-researchers want to influence how adults with Asperger's syndrome are supported. The plan is outlined below:

### **Conference plan**

Introductions and discussion of diagnosis



*Figure 10: Reclaiming the Triangle conference plan*

The conference demonstrates the way in which the co-researchers understood the data from the participants and how they related it back to their own experiences. The conference commenced with the co-researchers stating when they were diagnosed and explaining what they felt about having a diagnosis of Asperger's syndrome. Their diagnoses were presented as being historical events which had significance for each of

them. Katrina and Laura had very negative views of their diagnoses, which they stated but they also alluded to how being in the group has changed the way they thought of themselves.

Laura states: 'I haven't always been happy to be someone who has Asperger's. Joining the group has been a new chapter in my life with a positive influence. It has helped build up my sense of identity as a young woman with Asperger's.'

Co-researcher Katrina outlined how diagnosis for her had been very negative, but being a part of the group had challenged her negative self perception:

My diagnosis was a double edged sword in the sense that it explained my behaviour but also made me question a lot of things about my personality. When I was first diagnosed I believed that all my life goals were unachievable for me but within the group I am now achieving these things in different ways.

The significance of this is that the co-researchers acknowledge the negative influence of being diagnosed with Asperger's syndrome, which many participants from the focus groups and individual interviews also expressed. However, these two co-researchers have experienced working in our group as positive and this had helped give them a more positive sense of identity. They used a new experience, that of working in our group to challenge the validity of their previous experience. This set the tone for a conference where experience would have a central role. This was the co-researchers' opportunity to challenge negative attitudes about Asperger's syndrome, to show what they had achieved in the research (which in and of itself is a challenge to the deficit model) and to propose a new way of understanding Asperger's syndrome, which has the potential to change the experience of other adults with Asperger's syndrome. The co-researchers had agreed that the experience of being a part of the research was an example of how the Triad of Understanding worked i.e. they felt understood, they understood themselves in the group and they understood other members. They had discussed how this mutual and self understanding had led to the success of the group

and they wanted to use this as an example to the conference attendees. When talking of her motivation to join the research group Katrina detailed her hopes but also her low expectations:

I joined the research because I was looking for something that would help me understand my personal experience of having Asperger's. In all honesty, I had little expectation of finding it and I didn't believe in the group and I certainly didn't expect to be stood here today.

The co-researchers knew that we had co created a way of working together that they had not experienced before. Laura comments:

I also wanted to work alongside a professional worker and develop a different kind of relationship as Jackie has worked with me rather than be there to support me. I wanted the chance to be truly me in a group of equals. I thought there was no better chance of doing this than in a group where others have Asperger's.

Duncan's previous experience of research had mirrored his experience of being in society. He has been regarded as different and a fitting subject of research. He had taken part in a research project where he had been observed in order to document his ability (or lack of ability) to maintain eye contact. He valued the difference between being observed from a deficit model and instead being treated as an expert and being central to the research: 'I had previous experience of being a research subject where I was observed to see how I reacted. With the group I was treated as an expert in the subject as I live life with Asperger's.'

When we presented the findings of the research, the key role that each member in the group played was made clear. Katrina explains how she felt about being in the group:

I had no experience of the joys of being part of a group until joining this one ...a place where my intelligence will be respected but not taken advantage of. For the first time in my life I feel like an equal and this has allowed me to reach my full potential ...The group itself has become a great example of how the Triad of Understanding can benefit people.

After the findings were presented and the triads of understanding and misunderstanding were explained, each co researcher spoke about their own lives and the significance of the triads to them. Laura enthusiastically proclaimed:

The triangle is life's godsend! It makes so much sense to a lot of people. When I first seen the triangle I thought yes this is it, this is what I've been searching for, the triangle just made complete sense of the cycle of our lives and what things can have a direct influence on others. It was my answer.

Katrina explains the link we had made between our triads and the triad of impairment:

The way in which we have presented our findings is particularly significant as the more familiar way that people are presented with understanding Asperger's is through a triad of impairment. We wanted to present a more inclusive model that represents not just the person with Asperger's but the network of people around them. Understanding individual people with Asperger's involves everyone.

The co-researchers had decided that the best way to explain how the triads worked was to apply them to their own lives. They used past experience to show why the triads were valuable and also give examples of how they could be applied. Laura and Duncan both spoke about this with their mothers. Duncan's mother explained how Duncan's family had tried hard to understand Duncan and had helped Duncan understand other family members:

Instinctively, we have worked through situations together where we have supported each other in mutual understanding without realising this is what we were doing. If we had the Triad of Understanding when Duncan was growing up, things would have been a lot easier for us as a family.

Duncan talked about difficulties he had when he was a child and a young man because he did not understand people and often felt misunderstood. He concludes: 'I would like the Triad of Understanding to be a legacy for other people with Asperger's and their families. I wish we had this when I was younger so my life would have been a lot simpler.'

Katrina spoke about her social worker who had helped her understand herself and had supported her after she had been diagnosed. She explains how the social worker supported her to understand herself in a way which was individual to her rather than being about the medical definition of Asperger's syndrome:

This working relationship encompassed everything about the 'Triad of Understanding'. That person helped me to understand what having Asperger's meant to me. The focus wasn't on understanding the ins and outs of Asperger's it was about understanding the way in which it affected my life and the lives of those around me. It was about understanding myself as an individual and how I relate to others.

Katrina made the link between how this better self understanding helped her explain herself to others: 'This person helped me to understand myself and by doing this enabled me to help others to understand me. This approach involved everyone understanding each other.'

Katrina then applied the need for mutual understanding to her relationship with her mother and how applying the triads to situations had helped them:

It was assumed that any problems within a relationship were my fault because I didn't think properly. No one ever looked into mutual responsibility and mutual understanding. We never considered the impact that we had on each other's lives. My Asperger's affects all aspects of my life and so it makes sense that it also affects everybody that is in my life.

For Katrina, the insights that the triads gave her enabled her to think totally differently about her relationships. She reflected on the 'damage' that was done to her relationships by taking a more deficit approach to Asperger's syndrome: 'It took ten years for me to realise that not everything was my fault and in that ten years a lot of damage was done to my self esteem.'

Katrina was able to look back at her experience of diagnosis, which was largely negative but to see that the support she did receive from her social worker was in two of the areas covered by the Triad of Understanding.

Laura summarised the significance of the triads for her: 'These are the things that surround my condition - me understanding myself, me understanding others and others understanding me'.

Laura and her mother spoke together at the conference as did Duncan and his mother. Laura's mother spoke of some of the misunderstandings between professionals and Laura and the harm that she believed this had caused Laura. Talking of the insights provided by the triads she reflects:

If she has these understandings, she will be able to succeed in life and be happy. This is the way forward and Laura will not fulfil her potential unless this

triangle of understanding is in force. We hadn't succeeded because of the misunderstanding. The triangle of misunderstanding shows what we had experienced. Laura will not go forward and succeed in her life unless we use the ideas from the triangle to look at why things go wrong as well as how to make them better.

Laura comments:

I am me and I am proud to stand up and say that I have Asperger's. It is not all me but it a significant part of me. I don't want to change and I can't change who I am but I want to get on and succeed in life and do what I feel I have to and the triangles are a way forward and will help me.

Laura and her mother powerfully demonstrate the usefulness of the triads. They show how the triads offer a way of understanding what goes wrong for people with Asperger's syndrome as well as the potential for changing this for the future. As Laura says, she cannot change and does not want to change who she is. The triads have presented a framework for people with Asperger's syndrome to be 'who they are' and for this to be understood by themselves and other people, and for other people to take responsibility for trying to understand the person with Asperger's syndrome. The co-researchers drew on two sets of experience for the conference. They talked about their experience of having Asperger's syndrome and how this had affected their self esteem due to the way they were misunderstood or poorly treated. They reflected on this experience by using the two triads to determine why they had such negative experiences. The second set of experiences covered their experience of being co-researchers for this research. They also saw this in terms of the Triad of Understanding and thought it to be an example of how it can be implemented. Both sets of experience they viewed through the perspective given by the triads. The triads in turn were formed through reflection on the experience of the co-researchers and other adults with Asperger's syndrome. The triads also influenced the way the co-



researchers viewed their past experience. Most significantly for future applications of the triads, the co-researchers thought they offered the prospect of a different experience for adults with Asperger's syndrome in the future. The conference was not just a vehicle for the co-researchers to showcase their abilities and display the positive experience of working together; it was also a vehicle to tell others about our theoretical challenge to the deficit model of understanding Asperger's syndrome.

#### **b) Trying to influence the experiences of others**

The co-researchers knew who was due to attend the conference as we had looked at the list of prospective attendees together. We knew that over ninety people were due to attend. Many of them were either professionals who worked with adults with Asperger's syndrome or parents or foster carers of young people with Asperger's syndrome. Having established the relevance of the triads to the experience of the co-researchers, the co-researchers wanted Katrina and myself to go on to apply them more widely. (Although we each wrote what we said in the conference script, we all had to agree what the other group members said so all that I said had been agreed by the three co-researchers). At the conference I explained the role that everyone has in the understanding between people with Asperger's syndrome and neuro-typical people:

What these models indicate is that people who do not have Asperger's syndrome have a role in supporting people with Asperger's syndrome to understand other people but they must first try and understand the person with Asperger's. All three corners of the triad are interlinked. Our data shows that people without Asperger's can help people with Asperger's to better understand themselves. ... In order to do this, people without Asperger's must first understand the person with Asperger's.

Katrina explained the view of the group that the triads of understanding and misunderstanding were about individuals with Asperger's syndrome and those they

interact with, not an explanation of what Asperger's syndrome is: 'We feel that in order for the triads to work best people with Asperger's should be treated as individuals. The aim is to understand a specific person's experience of having Asperger's rather than a textbook explanation of what having Asperger's means.' We had decided to conclude the conference with some case studies which we had written (Appendix 15) and asked participants to work in groups to address the question: 'How might the Triad of Understanding be helpful in this situation?' These case studies were based on the experiences of the co-researchers and outlined situations where they felt they had been misunderstood. The co-researchers thought that the research demonstrated that their experiences were mirrored by other people with Asperger's syndrome and so would provide a useful basis for discussion at the conference.

Feedback was taken from each group and presented back to the whole conference. Each group was asked to use the triads as tools to discuss each case study and then report on how useful the Triad of Understanding was as a tool for analysing social situations.

We had chosen each case study to highlight the application of the triads in a variety of situations and contexts. We wanted the attendees to practice applying the triads so they could see their potential as tools for understanding the experiences of people with Asperger's syndrome when life goes well and when it does not. We used the experience of the co-researchers and the data from the research to highlight aspects of life which people with Asperger's syndrome can struggle with. This included understanding changes in relationships, the need for routine, anxiety due to demands made, coping with a new relationship and confusion around identity.

The exercise went positively and the attendees clearly understood the triads and their relevance. Each group fed back many points about how the triads could give insight to the person with Asperger's syndrome and the neuro-typical people alike in each study.

### **Attendees' feedback on the Conference**

The co-researchers received many positive comments at the end of the conference which indicated that the attendees had been impressed by what they had achieved and also by the potential of the triads. We also wanted a record of the reactions of the attendees to the conference so we had designed a feedback form (Appendix 16).

The first question we asked was whether or not the attendee had a 'formal diagnosis of Asperger's syndrome'. Of the ninety three attendees at the conference, sixty four completed feedback forms. Fifty five attendees who returned the feedback form stated that they did not have a formal diagnosis and nine said that they did (none of these had been participants in any stage of the research). Some who said that they did not have a diagnosis underlined the word 'formal' and said 'no' to that, indicating that they thought they might have Asperger's syndrome, but were not formally diagnosed. We asked 'What is the most important thing you've learnt from the conference?' Of the nine attendees who had been diagnosed with Asperger's syndrome, five stated that the application of the triads were the most important thing they had learnt. The others said that they had learnt that they could be successful in life and that each person with Asperger's syndrome is different. In answer to the question 'How could you implement the Triad of Understanding in your everyday life?' seven attendees with Asperger's syndrome answered and specified applications in their own lives. These applications included using the triad as an 'after the event tool' for understanding when situations 'go wrong', understanding more clearly the effect they were having on others, 'organising the process of relating to people better' and helping them understand the role of other people better. Others said the triads helped them be more aware that other people did not always understand them and also helped them realise that understanding was a two-way process with neuro-typical people needing to understand people with Asperger's syndrome to develop 'an effective relationship'. One attendee stated that the triad could be used by providers of services. In other words, all seven saw the relevance of the triads to their future experience.

The fifty five other attendees who completed the feedback forms were a mixture of parents of a child with Asperger's syndrome, foster carers, social care and social work professionals, health professionals such as speech and language therapists and a clinical psychologist as well as teachers and lecturers. The Director of Adult Social Care for the local authority also attended. We did not ask attendees to identify themselves in any way, so I am unable to analyse what different groups of people thought. The majority of attendees made at least one of these five points:

1. The triads offer a new and effective approach to working with people with Asperger's syndrome
2. From the triads and the explanations given by the group, the importance of not making assumptions about people with Asperger's syndrome but treating them as individuals was important
3. Previously attendees had seen the 'diagnosis' but the triads encouraged them to see the individual person
4. Communication is the key to understanding each other
5. The triads could have a wider application than to that of people with Asperger's syndrome

One attendee stated that they had seen a 'new paradigm of awareness', further illustrating the potential for a wider application of the triads in other contexts.

In response to the question relating to how attendees could implement the triad, it was clear that they thought they could be applied and gave the following examples for application:

1. The triads can apply to anyone in many situations, as one attendee stated 'in every aspect of life, home, work, understanding and communicating with others'
2. The triads are useful tools for conflict management and problem solving
3. Attendees intended to use the triads with family members, friends, and working with service users

4. The triads have the potential to be used as a basis for community care assessments, transition planning from children's services to adult services and also to support planning in community care.
5. The use of the triads in service provision emphasises supporting people with how they think about themselves rather than with their presenting needs.
6. The triads have a much wider application than with people with Asperger's syndrome. Attendees stated that they intended to use the triads with University students, for peer mentoring as well as teaching on a communication module and also in working with people with a learning disability.
7. The triads could form the basis of communication courses generally, not just involving people with Asperger's syndrome

The first point in the list above has been expressed informally to me by other people who hear about the triads. The potential of the triads to be applied to the experiences of everyone, whether or not they have Asperger's syndrome, was apparent at the conference through the discussions of the attendees. It is also implicit in a number of the other points. It is a wonderful irony that a model which has the potential to be used in any situation which involves people interacting with each other should emanate from research where the three co-researchers involved are said to have a deficit in communication (according to the triad of impairment, Wing, 1991). As I write this chapter, a conference is being planned at De Montfort University for September 2014. This conference is using the triads as a basis for exploring best practice in enhancing the student experience within the University. It was gratifying to see feedback which is summarised by point 3 above, that attendees intend to use the triads with their own family members, friends and service users.

Point 5 above summarises views of attendees that the use of the triads in services is concerned with 'how they think about themselves rather than their presenting needs'. This is an important point. The term 'presenting needs' was introduced by SCIE (2013)

in the document 'Fair Access to Care Services Guidance on Eligibility Criteria for Adult Social Care'. This document details how to assess adults in relation to their 'presenting needs' to ascertain their eligibility to services. We wanted to be able to influence services and how people with Asperger's syndrome are supported. Supporting people in relation to 'how they think' is supporting people in relation to their experience and how they understand this. Some attendees realised that the triads offer a different way of perceiving service users. Each local authority has a duty to assess people in relation to their 'presenting needs' and then which of these needs is 'eligible' for services. Instead of thinking purely in terms of these needs, the triads offer the possibility of thinking of service users with Asperger's syndrome in relation to their experience in relating to other people, and other people in relating to them.

There was some feedback about the programme of the conference which suggested improvements, the most significant of these being about how it could have been made more accessible for attendees with Asperger's syndrome and I will address these in the next chapter.

The feedback was very positive and it does show the potential of the triads of understanding and misunderstanding as tools to support people with Asperger's syndrome and to assist neuro-typical people in understanding interactions between them.

## **2) The website**

As stated in Chapter Six, the second way in which the co-researchers wanted to disseminate the findings was through a website, which has now become a blog. The purpose of this website was to be able to disseminate the findings of the research but also to provide a vehicle for the group to have a presence where they could tell others of their own reflections. The co-researchers think that the triads of understanding and misunderstanding offer a different approach to understanding Asperger's syndrome and as such offer the possibility of people being supported in a more appropriate way.

We designed the contents of the website as a group and each member described their view of Aspergers' syndrome. The significance of these reflections is that they are at the end of our data analysis period and they evidence how each co-researcher has understood themselves in the context of living in a neuro-typical world; they are based on their own experience rather than any text-book definition of Asperger's syndrome. Co-researcher Laura highlights how she understands the world in a different way to neuro-typical people:

Not everybody is very understanding of people on the autistic spectrum. Some people in my life have been very helpful and others haven't. Acceptance of myself has been affected by other people's views and how they have treated me. It gets me frustrated because people without Asperger's don't know deep down how I see the world. Others see Asperger's as weird but it is a part of me and I think because I have Asperger's, I have been able to relate to other people with needs or difficulties.

Katrina expresses the ambivalence with which she views Asperger's syndrome but is clear that she needs to be treated as an individual person, whilst at the same time acknowledging that she has Asperger's syndrome:

I feel it is very important to be treated as an individual and I get the most out of life when other people respect my Asperger's and also accept what I am saying as the truth. No one knows my condition as well as I do. My attitude as a young person with Asperger's has changed a lot since diagnosis, sometimes I feel okay with having Asperger's and others times I hate it. I'm not sure if I will ever reach a point where I have a definite idea of whether it is good or bad, perhaps it will always be a mix of both.

Duncan summarises the struggles that all the co-researchers had faced:

As individuals we have all struggled with a sense of identity. Who do we look for to form our sense of identity when we are different from those around us? We have needed reassurance that we are doing what is expected of us and understanding the unwritten rules of behaviour. By meeting other people with Asperger's and sharing experiences within the group we have developed a better understanding of ourselves and gained a more positive identity as adults with Asperger's. It is this understanding which informs all the work that we do.

Duncan clearly identifies the understanding of himself that he had gained through the experience of working as a co-researcher and the positive effect this had on his own sense of identity. It is from a positive sense of identity as individuals that the co-researchers want to consider the shared experience of living in a neuro-typical world. In doing so, they want to influence service provision and people that support people with Asperger's syndrome.



## **Chapter Nine**

### **Discussion I**

In this and the following chapter, I will consider the findings in light of the literature reviewed in chapters one to four and will highlight new areas of knowledge. This chapter will consider the process of undertaking the research, and in Chapter Ten I will present a discussion of the findings.

The title of this thesis is: 'Participatory research with adults with Asperger's syndrome: using spatial analysis to explore how they make sense of their experience'. Spatial analysis will be employed later in this chapter when it will be used as a framework for discussion and evaluation.

The aims of the research were:

1. Use a participatory approach to explore how adults with Asperger's syndrome make sense of their experience of living in a neuro-typical world.
2. Reflect on the use of the participatory research approach with adults with Asperger's syndrome
3. Reflect how the principles of participation be most usefully applied in other contexts so that adults with Asperger's syndrome are more able to reflect on their experiences and express what they need from services.

As outlined in the introduction, these aims all relate to the research question: 'What support do adults with Asperger's syndrome want?' All three of these aims will be addressed in this chapter and the first and third aims will also be addressed in Chapter Ten in the context of the outcomes of the research.

This research has explored new ground in two main areas, the use of a participatory research framework with adults with Asperger's syndrome and the fact that new knowledge can result from employing such as process. In other words, it has explored process and outcomes. It is to the first of these that I now turn.

## **The process of the research**

### **1. Disability, Asperger's syndrome and co-creating a research space**

In Chapter Three I discussed the disabled people's movement as well as the social model of disability. I traced the struggle that disabled people have had in the attempt to realise and enjoy the same rights as non-disabled people. I discussed this from a spatial perspective and noted Freund's (2001, p. 710) assertion that 'Inhospitable spaces can become focal points of resistance'. Freund was referring to the literal spaces where disabled people were sent, away from society. People with Asperger's syndrome have a different experience. They are excluded, not physically but through a lack of understanding and acceptance. To people with Asperger's syndrome, the 'inhospitable space' is neuro-typical dominated society. It was through the process of the research that another space was created, a disclosive space, which allowed for the possibility of change (Dreyfus, 2004). In this space the co-researchers and I had a common purpose of exploring issues of support and service provision. In the disabled people's movement I noted that what took place was the formation of a common identity and the joint purpose of resisting the medicalised and 'tragedy' identity placed on them by society. There are parallels to this in this research as well as differences. I cited Campbell and Oliver (1996, p. 110) as saying that the disability movement was about 'the struggle against oppression, against segregation'. Although the research was intended to explore service provision and support for people with Asperger's syndrome, it was the separation that co-researchers and participants felt from society which underpinned the findings and influenced the direction of the later phases of the research. The creation of a disclosive space meant that we could explore ways of thinking that were different from those outside of the space. In our disclosive space we created different relationships of power to those outside of the space, allowing us to see how relationships of power could be changed outside of the space.

Foucault linked power and knowledge (Foucault, 1980) and I have discussed how this can be applied to the discourse about people with Asperger's syndrome being seen from a deficit model. As explained throughout this thesis, we wanted to base this

research on an application of the social model of disability. The social model of disability, as noted in Chapter Three was based on the belief that difficulties experienced by disabled people were the result of living in a society that did not accommodate them rather than being the result of their impairments. Disabled people are subject to the exercise of power through the operation of the 'medical' model of disability. The linking of impairment and disability maintains the inferior power position of disabled people as they are thought to be deficient and so the cause of their own difficulties (Oliver, 2009). However, as Oliver and Barnes (2012, p. 22) state: 'This social model breaks the causal link between impairment and disability'.

The social model shifts attention away from impairments to what people experience in common from a disabling society. I had not read of the social model specifically being applied to autism or Asperger's syndrome and I wanted to explore its relevance. I have already outlined how I discussed the social model with the co-researchers. What I wanted to explore was how the social model could be applied to working with people with Asperger's syndrome and also see if our findings were compatible with it.

I discovered that we were indeed able to apply the social model to working together. I reflected earlier on the importance of this discussion for the group and how it set the tone for how we worked together. The first discussion in the group of the social model acknowledged that it is society that causes difficulties for disabled people. One of the co-researchers was immediately able to apply this to a physically disabled relative and after further discussion the co-researchers could see the relevance for themselves. As some of the co-researchers believed that they were failures and attributed this to having Asperger's syndrome, the discussions were significant for them personally as well as for the group. As we set out to co-create a research space that was based on an understanding of the social model, it may be unsurprising that the discussion and subsequent analysis of the data was consistent with the model. In Chapter Three I cited Shakespeare as stating: 'I would argue that any qualitative research with disabled people will inevitably reveal the difficulty of distinguishing impairment and disability' (Shakespeare, 2006, p. 37). In the social model, disability is understood as being

socially based, whereas impairment is biologically based and Shakespeare challenges this distinction: 'There can be no impairment without society, nor disability without impairment' (Shakespeare, 2006, p. 34).

The findings in this research have concurred that there is a distinction between impairment and disability, although that is not the language used by the co-researchers, respondents, participants or myself. The co-researchers understood their experience as what they shared in common; that is their experience of being misunderstood and misunderstanding. Although the findings are framed in terms of 'understanding' and 'misunderstanding', the collective experience of people with Asperger's syndrome in a world that is organised by and for neuro-typical people has direct parallels with the social model. This can be reframed to say that people with Asperger's syndrome are disabled by being in a world which excludes them and creates social barriers to their inclusion. As a group we never used the word 'impairment' as we preferred to refer to 'differences'. (It is another discussion as to whether Asperger's syndrome is an impairment as it is my position that it is a different way of thinking. However, for the purpose of this discussion I shall equate Asperger's syndrome to the concept of impairment as discussed by Shakespeare.)

Spatial metaphors are useful to aid this discussion. When people with Asperger's syndrome are able to organise their own spaces (for example the Autoscape conference discussed in Chapter Two) or physical environments they are able to function well and 'cope', they do not experience their Asperger's syndrome as disabling. During group discussions, the co-researchers discussed their need to organise their own physical spaces where they live and how this enables them to feel literally 'at home'. It is when people with Asperger's syndrome have no control over the spaces that they inhabit and so have to try to cope in the space of neuro-typical people that they are 'disabled' or cannot 'cope' (to use the language of the co-researchers). There is here a clear separation of disability and impairment. As discussed in Chapter Three, Shakespeare criticised Oliver's application of the social

model to employment and stated that if all societal barriers were removed then some disabled people would still be unable to work (Shakespeare 2006). Whether this is true for people with Asperger's syndrome is difficult to assess. However, the findings have shown that people with Asperger's syndrome would like support to understand the world better and if this is achieved, it seems reasonable to think that many would be able to cope better in many environments, including the workplace.

I discussed in Chapter Three how some disabled academics have written about *impairment effects* (Thomas and Corker, 2002) and I suggested that *difference effects* would be more in keeping with avoiding a deficit based understanding. The findings do indicate that it is the difference effects of people with Asperger's syndrome that cause them difficulties in a neuro-typical world. This is totally consistent with the findings of the research as the triads of understanding and misunderstanding are designed to address the misunderstandings of neuro-typical people as well as the difference effects on the person with Asperger's syndrome. Both need to be addressed in order for a person with Asperger's syndrome to be able to cope in a neuro-typical world. What this research has shown is the significance of an understanding of disability based on the social model. An emancipatory space utilises the knowledge that is grounded in the circumstances of everyday life and is 'illuminated' by the struggles of co-researchers (Oliver, 1992). I detailed in Chapter Eight how the experience of the co-researchers was the foundation of our research. This knowledge was used in the context of a shared understanding of disability based on our discussions of the social model. The experience of the co-researchers was 'illuminated' by the social model. The co-researchers had previously framed much of their experience in line with a deficit model. Our research space was based on our understanding and application of the social model and also provided us with an environment in which to consider it further. Data was considered and analysed and knowledge produced based on our understanding. In our work, we continued to explore the difference between 'impairment' and 'disability' in that we produced knowledge that focused around the

disabling effects of being misunderstood and misunderstanding. This was only possible in a research space which was itself an example of the removal of disabling barriers.

## **2. Spatial analysis**

The second aim of this research was to reflect on the use of the participatory research approach with adults with Asperger's syndrome. As part of my Literature Review, in Chapter Two, I proposed a 'spatial analysis framework' based on the work of Urry (1995), which I will use to discuss the research and consider how participatory research worked. Urry's work centred on literal physical spaces, but I used it to think of what happens in metaphorical spaces as I recognised the potential application of it to consider issues of power and control in relation to participation. The essential questions arising from this framework are:

- What is exclusive or unique about a space?
- How is a space further divided and by whom?
- What knowledge is being utilised in a space?
- What happens in a space? Who sets the agenda for what happens? How is this achieved?
- How do those in a space experience it?
- How are social interactions in a space different or the same as those in other spaces?
- How does a space relate to other spaces?
- How does a space change? Who is responsible for the change? How is change achieved?

As stated in Chapter Four, the participatory space is a metaphorical space, 'a space that is the sum of interactions between service users and the researchers or organisation which has 'invited' their participation, whether that be in relation to services or research activities' (p. 112). As the participatory space is one where I and the co-researchers interacted, it focuses on the roles of all, hence on the experiences of all rather than just one party.

I shall refer to the participatory space as the 'research space'.

**i) What is exclusive or unique about a space?**

One of the key characteristics in this research space when compared with the experience of group members in society is the consideration given to power and cultural practices. I noted in Chapter Four Lukes' (2005) discussion of how cultural practices can suppress some conflicts while mobilising others. Lukes also discussed how power can operate through what is not done as well as what is actually done. This was important in considering how the research space was to be co-created. I wanted to ensure that my neuro-typical bias did not dominate the space and so suppress the preferred cultural practices of the co-researchers. I also noted Smith's (2008) discussion of the interplay of the identity of the professional in terms of standing and authority and how interactions with service users mean that power operates through multiple sites. Although my role was as a researcher, I also had to consider that I had developed professional practices as a social worker where I was used to assessing service users and having the authority that goes with that role. I had to consider how to practice differently and how to work with the co-researchers in the co-production of our research space. I was also aware that all three co-researchers had their own social workers and were very familiar with working with them in a relationship where the social worker was the powerful professional. This research space could not mirror those power dynamics if it was to be a truly participatory space.

Smith (2008) proposed a framework of understanding, exploring, reframing and changing power relationships (Smith, 2008, p. 150). The co-researchers and I *understood* and *explored* power relationships through our discussion of the social model of disability and through the type of research that we wanted this to be. I thought it vital that any understanding of power issues was based on the social model and this is where our discussions were rooted. Campbell and Oliver (1996) had discussed the inclusion of non-disabled people in organisations for disabled people. They had cited Finklestein who wrote that groups for disabled people needed to develop a clear understanding of disability before they allowed non-disabled people to

be part of the organisations. If this is not done, according to Finklestein, the non-disabled people will change the organisation to suit themselves. It was impossible to work in the way that Finklestein suggested as I formed the group and we wanted to work together. However, right at the outset of our meetings, I wanted the co-researchers to think about the social model of disability and its application to them and to how our group was to function. Finkelstein's caution was an important one for me to heed and ensure that I did not act in ways that could be open to this criticism. A consideration and application of the social model was important for myself and the co-researchers to consider together. The challenge was to allow for the potential of all four of us thinking differently about Asperger's syndrome and how we could work together to create an environment which was not disabling and to *reframe* the power relationships. Oliver stated that 'all disability can be eradicated by changes to the way we organise society' (Oliver, 2009, p. 44). We wanted our research space to be unique as it would be based on the principles of the social model. The co-researchers were acknowledged as the 'experts' rather than myself and in so doing, power relationships were reframed.

Barnes (2012) had referred to the 'colonising' of organisations for disabled by people by non-disabled 'experts' (Barnes, 2012, p. 174). The relationships were *changed* through building on the understanding that the co-researchers were 'experts' and then acting on it. The way we worked together meant that the co-researchers were respected and acknowledged as experts. We worked together in such a way that everyone in our research space was able to have a voice and that voice was listened to and acted on. Every member shaped the research in different ways.

The main way we explored power relationships was in thinking through the implications of the co-researchers being adults with Asperger's syndrome and myself being a neuro-typical adult. Although we also acknowledged that I am a professional and therefore am in a more powerful position to them, we did not explore this power dynamic to the same extent. On reflection, I could have encouraged a deeper consideration of the power dynamics in relation to the professional/service user



dichotomy. Although I was aware as shown above of the power imbalance in relation to professional status, I was far more aware of the Asperger's syndrome/neuro-typical difference and so this is where our discussions were focused. This had the effect of changing power relationships as the co-researchers responded very positively to thinking of themselves as experts whose opinions were valued and their contributions to the work acknowledged as essential. This made the research space unique for all of us. Katrina spoke at the conference about how she experienced being part of the group:

Prior to joining this group I believed that I couldn't work well with other people. Every time I had tried to work with others I had failed, be it in school, work, anywhere. Working with other people had always led to me getting bullied because of my intelligence or people in the group have put so much pressure on me to do so much that I then become incapable of functioning and have to quit. I had no experience of the joys of being part of a group until joining this one. Laura, Duncan and Jackie have shown me that I have a place within a group.

This research space was a different space to any that the co-researchers had experienced. It was also a different space to any I had experienced. For me it was a unique experience due to the open consideration of what it means to be someone with Asperger's syndrome and what it means to be someone who is neuro-typical. This was discussed in different forms every time we met both in terms of the research and more personally for the individuals in the group. Considerations of power were always present, although it was not framed in those terms. Instead it was framed in terms of differences and how these were perceived in society. Carr (2012) wrote of the importance of the way service users are treated in a participatory space as it gives them a clear message about their own value. It also demonstrates who is 'allowed' to have power and a voice. Carr (2012) also wrote of how a participatory space can 'model' how service users can participate in a wider organisation. In the context of this

research, there was not a wider organisation as envisaged by Carr. However, what the research space has shown to the co-researchers and others is what they can contribute. It has demonstrated that they as individuals have worth and can make valuable contributions as well as demonstrating that people with Asperger's syndrome can be successful in group situations, as long as the groups are managed in an enabling way. It has demonstrated that if a space is enabling then they can understand others and also be understood. It has demonstrated how a research space based on the principles of the social model can be enabling. It is a testimony to what can happen when 'disabling barriers' are removed (Oliver, 2009). Oliver (2009, p. 110) wrote that 'participatory strategies' do not confront the structures of oppression and so still position disabled people in oppressive ways. As I reflected in the Literature Review, this does not allow for the possibility of a research space avoiding replication of the inequalities in society. Beresford (2005, p. 10) does allow for the possibility of research working for everyone providing issues of access and support are addressed. Access is concerned with 'structured, ongoing ways of being involved; of engaging with services and agencies, of getting in and connecting with structures of organisation, management, control and decision making'. Support is where 'people can expect to have whatever help, support, encouragement, information and skill development they may each need to contribute what they want to, how they want to'.

This research was unique in that support was available in the way that we worked together. Each co-researcher worked according to their strengths and was involved in the activities that they chose. The skills of us all were developed during sessions as we found ways to work together and to design the research. Our space did not directly relate to other organisational spaces in the way that is implied in Beresford's definition of 'access'. It does not allow for participatory research which is not commissioned by an organisation. However, the intention of the group was always to influence services and the conference and website were intended to fulfil this role. This does not accord with 'structured, ongoing ways of being involved' and indeed, this was not an option in the way we worked. Our research space was co-created independently of any

organisations. Rather than 'access' being one of the criteria for measuring how power is shared, the fact that we were independent of organisations meant that we could concentrate on how we worked within our group together. However, we did have a relationship with the local authority as they supported the research. This was a very positive relationship, particularly with the Asperger's team who helped with access to participants for the questionnaire and were part of the piloting. We also held the conference at County Hall so the link with the local authority was made clear to attendees.

We did however experience some difficulties in a reversal of what Beresford refers to. Some staff from the council which supported this research wanted to gain access to our research in a way that was against the spirit of the arrangement with the local authority. It had been agreed that we would acknowledge the support that we had received from the local authority in any dissemination and that they could inform any inspectors that they had supported the research. What I discovered was that other sections of the local authority came into play when the conference was being discussed. These did not seem to share the same values as the social work practitioners we had worked with. Some members of staff from the publicity department wanted to put the local authority's logo on the conference flyer and I had many difficult discussions and emails in rebutting this suggestion. The co-researchers and I had discussed the issue and agreed that this was an important principle. The only logo we had on our flyers was the one the group designed for themselves. In effect, the officials wanted to 'colonise' our research and claim it for the local authority. I was even called 'a disappointment to adult social care' during one phone call as we refused to concede this important point. If Beresford had used spatial terms, he might have talked about research spaces extending to other organisational spaces. What we experienced was the organisational space trying to extend into our space. Its uniqueness would have been compromised had this happened.

I have learnt that non-disabled researchers can work with co-researchers to create a unique space, providing that the co-creation of the space is based on the social model

of disability. I am not excluded from an autistic space because I am neuro-typical. I have a role in co-creating this space. It is unique as a result of the considerations given to co-creating it. These considerations are not given in wider society. Its very uniqueness demonstrates the dominance of neuro-typical people in other spaces. It has shown me the richness of insights that can be gained through creating spaces where people work together to understand each other rather than regard others from a deficit model.

**ii) How is a space further divided and by whom?**

The research space was divided in a number of ways, all of which informed the way we worked together. It was divided by roles, tasks, sessions and stages of the research. Each of these divisions was agreed by the co-researchers and myself. As discussed in the methodology chapter, we agreed how to conduct the meetings in terms of roles at an early stage. Also, my own view of empowerment had been to encourage group members to take on formal roles and to support them with this. The co-researchers helped me to understand that this is not an approach that would be helpful to them. I had to learn not to bring my previous experience of working in this way to the group. Instead I learnt that the best way of working together was for the co-researchers to work in ways with which they were comfortable. We employed a model of self-directed groupwork. Mullender, Ward, Fleming (2013, p. 11) write that self-directed groupwork has:

opened up opportunities for people whose potential to take action on their own behalf has been stifled by externally based restrictions and by limiting self-beliefs and assumptions telling them that they do not have the abilities, rights or scope to act.

This is a very apt description of the co-researchers' previous experience. The process of the co-creation of our research space was very important as it would be in the process of working together that the co-researchers would experience empowerment.

Mullender et al (2013) suggest a self-directed groupwork model, the second stage of which is called 'The Group Takes Off'. In this model, a 'working agreement' is formed which covers rules, recording and facilitator roles. ('Recording' and 'rules' will be discussed below). For myself and the co-researchers, this meant how we would work together. We all learnt to respect what each other was comfortable with and to use the strengths of each member to help the group as a whole. The group assigned nicknames to each member. Duncan was called the 'data guy' as he enjoyed and was good at remembering all the themes and understanding them numerically. Laura was named the 'enthusiast' as she was always encouraging to other group members and Katrina was called the 'thinker' as she was very good at using language to summarise the thoughts of the group. I was nicknamed the 'navigator' as the group said I kept them on track, recognised the strengths of each member and provided direction when it was needed. These nicknames show a clear understanding of the role that each of us played but not in the usual sense that might be linked to stereotyping tasks within a group (for example chair and minute taker). The co-researchers and I have written an article in which we reflect on the roles assigned within the group (Martin et al, 2014). We discussed how the roles evolved rather than were assigned and each co-researcher expressed how they felt the roles suited them. We wrote:

These were not initially formalised as roles but rather activities which each member felt comfortable to take part in. Over time, the group recognised that each member did perform a unique function in the group and this led to the group recognising these as 'roles' (Martin et al, 2014, p. 71).

The usual view that people with Asperger's syndrome do not have insights into social situations was certainly not the case here. In our research space, the co-researchers had very good insight into the role that each of us played and our individual characters and strengths. We did not assign roles in the way suggested in the model for self-directed groupwork above as this would have been a cause of anxiety for the co-researchers and they clearly expressed that they did not want to do this. We adopted

our own way of working where every person was ascribed a role according to how they wanted to work within the group. Benson (2010, p. 53) writes that every role in a group has 'a measurement of worth' and the assigning of nicknames to indicate the role within the group that each of us played was an acknowledgement from the co-researchers that all members have worth and make a unique contribution.

Chapter Five considered how each task was divided between the group members and this changed as the group grew in confidence. Mullender et al (2013) suggest that the issue of recording should be addressed at an early stage of a group. They indicate that it is not normally in keeping with a self-directed approach for a 'facilitator' to keep their own record and not share these with participants. Although the task of writing up notes of sessions was originally given to me as no one else felt they wanted to do this, all records were shared and agreed by the co-researchers. As the group grew in confidence, each of the co-researchers took turns to write up notes of our discussions directly onto the laptop computer.

We agreed our group 'rules' (Mullender et al, 2013) at an early stage and these were adhered to by all throughout the research. At the beginning of each session, we agreed how we would work together. We agreed the timings, when we would take a break and what work we would cover. We agreed what work was best done in the morning session and what in the afternoon session. Each co-researcher used the free time at lunch time to do different things and this was also an important part of how the sessions were organised. This happened every time we met. There was no expectation that the co-researchers should stay as a group. This was as important as the way we organised the time. It enabled the co-researchers to organise the whole day in the way with which they wanted.

Each stage of the research was discussed as a group and the co-researchers were able to take part in particular stages or opt out if this was what they wanted. This also proved an important strategy as one co-researcher was not happy to be part of the focus group stage. That co-researcher chose to stay away while the rest of the group

conducted the focus groups. We kept in contact with that person through regular email updates and they rejoined as soon as the data needed to be analysed. This was consistent with our rules as we had agreed that co-researchers would only take part in areas of the research that they felt comfortable with.

Our research space was divided principally by the co-researchers. We ran the group in a way that suited them and did not reproduce previous experiences of oppression. The facilitation of the process of agreeing the roles, rules and means of recording was done by myself with the full co-operation of the co-researchers.

### **iii) What knowledge is being utilised in a space?**

Warren (2007, p. 26) notes that one of the motivating factors for agencies being involved in participation is to gain an understanding of the subjective world of service users. Although Warren is referring to the experience of the social care system, the same principle applies to this research. I recognised that as a neuro-typical person, I cannot gain the subjective experience of what it is to be a person with Asperger's syndrome. The knowledge I wanted to be utilised in the research space was that of people with Asperger's syndrome as well as my own. It would have been possible to have designed the research tools on my own and to have then consulted people with Asperger's syndrome about their views of services. This would have been a much poorer piece of research as the richness and depth of the data and the data analysis was contingent on being able to utilise fully the knowledge of the three co-researchers, the respondents to the question, the participants in the focus group and individual interviews and myself. In the Literature Review, I reflect on Hickey and Mohan's (2004) writing on 'permeable arenas in which participation is invited'. I commented that 'bounded yet permeable' indicated the changing nature of a space. The space was changed completely by the invitation to the co-researchers to participate. The power was mine to invite, but the act of inviting changed the space. I was mindful that I wanted the space to be a positive experience for the co-researchers. In Chapter Four concerns about the 'voyeuism' of professionals and how professional

people can re-tell service users stories as 'problems' requiring a remedy (Gosling and Martin, 2012 p. 11) were highlighted. How the knowledge was used in the research space was as important as the nature of that knowledge itself. The knowledge itself will be considered in the second part of this chapter. It is noteworthy here that the knowledge was used to try to influence positively the experiences of other people with Asperger's syndrome. We wanted other people with Asperger's syndrome to experience a better understanding between themselves and neuro-typical people, as had been achieved in our research space.

**iv) What happens in a space? Who sets the agenda for what happens? How is this achieved?**

I documented in the methodology chapter and above how the group sessions were conducted. This all forms a part of what happens in the research space. From my Literature Review, the debate about empowerment is very relevant here. I noted Oliver's criticism of participatory research as being that sharing power is left to the discretion of the researcher (Oliver, 2009). He alleges that unless disabled people have complete control over their own research, they are in an inferior position to the researcher who controls the research. A discussion about what happens in a research space and how an agenda is set and achieved is relevant here. It is doubtless true that if I had decided to control the agenda then the research space would not have been an enabling one. However, apart from the original aim, which had to be stated prior to starting any research, everything was agreed between myself and the co-researchers. I disagree that disabled people are inevitably in an inferior position to non-disabled people in relation to participatory research as Oliver states. The idea of a research space as discussed throughout this thesis is that it creates something different. It is an 'interrupted space' (Bolzan and Gale, 2011). This is a space where people can explore 'new ways of being' (Bolzan and Gale, 2011, p. 505). Like Bolzan and Gale's space involving young people, the object of this research space was to share as much power as possible with the co-researchers. Just as in Bolzan and Gale's research, the co-researchers assigned meanings in ways that I could not have predicted. Bolzan and



Gale state that the young people were given the opportunity to 'experience agency in a resourced environment' (Bolzan and Gale, 2011, p. 513). Whereas Oliver doubts the possibility of anything but the experience of an 'inferior' position being experienced by disabled co-researchers, the concept of an interrupted space allows for the possibility of power being shared. It allows for the structural inequalities of society to be put to one side and for the people in an interrupted space to have a radically different experience. It is this different experience that allowed for the agenda to be agreed by all and achieved together.

**v) How do those in a space experience it?**

The definition I agreed in Chapter Four on participation included the purpose of achieving change beyond the group itself. I also noted that it is the process by which change takes place that makes service users feel valued. At the conference Laura spoke of how she experienced the research:

The research we have done has been interesting, powerful, unique and beautiful. All of the people who were involved in this have made it what it is. It has shown a huge and interesting contrast of life surrounding Asperger's and how people see their selves in a world of NT's and society in general. I think research is a very important key to success if people want to improve services and society for people with Asperger's in this world.

Duncan also spoke at the conference of his experience of being involved in the research: 'I found working together not to be a problem. There were no problems regarding our position in the group since we all played to our strengths. Having Asperger's didn't mean that I could not work well in a team.'

For Laura the experience was important as she could see how each member had contributed as well as the potential the research findings have for improving the lives of people with Asperger's syndrome. For Duncan, being part of the research showed him that he could work in a group. The way that the group had run enabled him to be a

part of it in a way that he had not experienced before. He found that it was not having Asperger's syndrome that had prevented him from being part of groups previously, but the way that they had been run.

As already noted, Katrina spoke at the conference of her experience of taking part in the research. It had been: 'A place where my intelligence will be respected but not taken advantage of. For the first time in my life I feel like an equal and this has allowed me to reach my full potential.'

The experience of all three co-researchers is positive and I would argue one of empowerment. Oliver (1992) states that empowerment must come from the co-researchers themselves rather than from the researcher. I maintain that the co-researchers were empowered as a result of the group working together, which included their work with me as well as with each other. As Barnes (2003, p. 8) wrote, emancipatory research is not about biology, but is about the commitment of researchers to put their knowledge and skills at the 'disposal of disabled people'. We have learnt what is possible if a research space is based on the social model of disability and becomes an interrupted space. We have learnt what people with Asperger's syndrome can achieve when the space is organised in a way that they are happy with. We have learnt that to enable people with Asperger's syndrome to be successful, mutual understanding has to take place. The co-researchers learnt from each other about living with Asperger's syndrome in a world that is dominated by neuro-typical people. Katrina gives us an example of this at the conference:

Duncan has shown me that I can be comfortable with who I am and not feel ashamed. He has shown me that adults with Asperger's can be proud of who they are. ... Laura has taught me that although life is hard you can go through it with a smile on your face and you deserve to be happy, she has shown me that people with Asperger's can be happy and this is something I am aiming for.

The experience of being in our research group was determined by the values of the co-researchers and myself. Mullender et al (2013) outline six principles that underpin self-directed groupwork. Although we did not explicitly identify all of these at the beginning of our research, those that were not stated were implicit in the way that we worked. I will draw on these six principles to explore how each shaped the experience of group members:

1. *Commitment to social justice.* As Mullender et al (2013, p. 49) state, self directed groupwork is about 'fighting for fairness, equality and justice'. Mullender et al (2013) cite Mullaly who uses concepts of injustice in groupwork before moving on to justice. Although we did not ever use the word 'justice' in our sessions, we did talk about discrimination and oppression and how people with Asperger's syndrome are treated by neuro-typical people. I employed a similar strategy to Mullaly in that I started our discussions about the social model of disability with the co-researchers' own experience of oppression. The experiences of the co-researchers were the foundations on which this research was built. Their own negative experience was a motivational force for them to try to find a better way of being supported for themselves and other people with Asperger's syndrome.
2. *People are experts in their own lives.* Mullender et al (2013, p. 52) write of facilitators: 'Our job is to uncover what is already there: to encourage people to use insights and knowledge they possess to bring about change in their own lives.'

The acknowledgement of the expertise of the co-researchers set the tone for a different experience for them. The use to which this experience was put was discussed in Chapter Eight. The acknowledgement of the expertise of the co-researchers went beyond insights to change their own lives, it included an acknowledgement of their expertise in interpreting what other people with Asperger's syndrome say about their experience. They were acknowledged as having insights into the lives of others because of their mutual experience of

having Asperger's syndrome and living in a society dominated by neuro-typical people.

3. *People have the right to be heard and to define the issues facing them.*

Mullender et al (2013, p. 54) in writing of the rights of the people they work with in self-directed groupwork state: The right to name their own world, to define themselves and the world around them, is something we insist on'.

Through centering the research on the experience of people with Asperger's syndrome (that is of those of the co-researchers, the respondents and the participants) it afforded the co-researchers the opportunity to define all three of these issues cited by Mullender et al, 2013). The experience of reflecting on their own identities and how they relate to neuro-typical people gave them this opportunity. The creation of theory in relation to themselves and neuro typical people and the presentation of this to professionals, carers and other people with Asperger's syndrome must be a rare accomplishment in this regard.

4. *Injustice and oppression are rooted in social policy.* Mullender et al (2013. P. 57) write that self-directed groupwork gives people the opportunity to 'break free' from the negative view of their problems as being individual to them and instead understand them in a wider political context. The co-researchers were able to discuss issues that they had experienced with each other and determine how these were shared more widely in the data we collected. Through discussion with each other and with me, they saw that although their difficulties were individual to them, there were commonalities with the experience of other people with Asperger's syndrome. Through a discussion of the social model they came to understand that the experiences were shared because of the oppression and lack of understanding of neuro-typical people.

5. *Collective power.* According to Mullender et al (2013, p. 58), the job of self-directed group work facilitators is to 'bring people together so that they can share their experiences and pool their resources and skills to fight injustice'.

The co-researchers did find strength from each other, as has already been discussed, and came to regard each other as role models in different regards. However, the collective power that was experienced in our research group also included myself. I was not just a facilitator but part of the pooling of skills and resources to fight injustice. The collective power was felt in the combination of people with Asperger's syndrome and a neuro-typical person. It was the 'pooling' of perspectives, understandings and skills that was resulted in the co-production of knowledge.

6. *Non-elitist ways of working.* Mullender et al (2013. P. 59) write that the expertise of the facilitator or 'groupworker' is in 'the skilled and sensitive implementation of the self-directed groupwork process, whilst group members define the content and outcomes'.

Whilst I think it is fair to say that the co-researchers experienced a non-elitist way of working, I also think that it is important to acknowledge that my role was more than is implied above. Mullender et al (2013. P. 59) go on to write that 'though special skills and knowledge are employed, these do not accord status and are not solely the province of the groupworkers'.

In our research, we also had different perspectives, which are not the subject of Mullender et al's writing. The dual perspectives of people with Asperger's syndrome and a neuro-typical person were crucial to the research. It is important to acknowledge this as the research is an example of how understanding can be achieved between people from the two perspectives, and an understanding which is not based on a deficit model. Also, it is my contention that the strength of the research is due to this dual perspective and it is through the two perspectives that we formulated the theory.

It was the combination of the exceptional systemising ability of the co-researchers and their understanding of their experience, and my understanding of being neuro typical, of deficit models of disability and of how to organise<sup>9</sup> the themes that gave rise to the triads. It would not have been possible without each perspective. Rather than detract from the experience of the co-researchers, this enriched it. They experienced working alongside a neuro-typical person who acknowledged their insights and was able to build on them. They experienced working in an enabling research space, which as they state on numerous occasions, is an example of how the Triad of Understanding works.

**vi) How are social interactions in a space different or the same as those in other spaces?**

The success of the research was based on the way social interactions were different in the research space from any other spaces that the researcher or co-researchers had previously experienced. The difference was that the interactions were based on an understanding of the social model of disability (Barnes, 2003). The co-researchers were used to situations in their lives going wrong, to being misunderstood and misunderstanding others. As a group we discussed how we could interact with each other and how we could make the experience different from previous experiences. We discussed the co-researchers' previous experiences of groups and why they had found these difficult. The reasons were usually concerned with other people not respecting them or respecting the way they would prefer to work in a group. They also thought that they had been regarded as incapable of contributing to a group. The co-researchers felt they had been viewed as recipients of services rather than people who could make a contribution in their own right.

**vii) How does a space relate to other spaces?**

The aim of the research space was to relate to other spaces. The motivation of the co-researchers for being a part of the research was to help other people with Asperger's

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<sup>9</sup> I mean here my suggested organisation of the three main themes into a triad, which I then suggested we call the 'Triad of Understanding'.

syndrome. Warren (2007, p. 26) wrote that 'outcomes, impacts on improvements and change, as a result of participation, are the primary purposes of participation'. This research space relates to other spaces in a number of ways. It relates as an example of how successfully people with Asperger's syndrome can work together on a complex research project. It also relates through its findings. The proposal of the triads of understanding and misunderstanding are the 'outcomes' of the research. It is through the findings that the research space relates to the neuro-typical world. It relates to that much bigger space by proposing tools for understanding how people should relate to each other. The bigger space is 'uninterrupted', it is the space where power is exerted over people with Asperger's syndrome and they are forced to try to behave in ways that they do not understand. It is the message of the interrupted space that people can relate differently if they are considered differently. If responsibility for understanding is mutually accepted then the neuro-typically dominated world can change.

I noted in Chapter Four Barnes and Cotterell's (2012, p. 73) assertion that participation is an 'overtly political process with objectives of enabling greater equality and more democratic decision making as well as securing improved services'. I also noted the importance of this statement in showing that a research space is also a political space. As a political space, it has implications beyond itself. The research space has shown not only how four people related to each other when working on a piece of research, it has shown how relationships can be organised differently. It has shown how power can be shared and mutual learning can take place. It has challenged the deficit model of understanding Asperger's syndrome. It is an example of what can be; a research space which relates to the much bigger space of the world of neuro-typical people.

**viii) How does a space change? Who is responsible for the change? How is change achieved?**

The research space changed as the group changed. It began as a tentative discussion of how Asperger's syndrome has been characterised in terms of a deficit model and a

consideration of the social model of disability. The space changed from the early stages of exploration with the co-researchers, where we were unsure how we were going to work together, to a space where each member knew they have a contribution to make and where all contributions were valued. It grew from a space to explore issues that people with Asperger's syndrome face to a space where all members felt that we have developed a tool for understanding Asperger's syndrome differently i.e. from one that explored problems to one that suggested solutions. It had changed from a space that was unsure about what contribution it could make to one where there is something radical to say. All members are responsible for this change and it has been achieved through the co-creation of a space which allowed for power issues to be reconsidered and power relationships to be restructured. In the context of this co-created space, the research was co-produced. From this co-production emerged a new way of thinking.

The application of spatial analysis and reflections on the process of our research has suggested possibilities to wider applications. I will consider below applications for co-creating a research space with co-researchers with Asperger's syndrome.

### **3. The triads and spatial analysis as tools for planning and evaluation**

The third aim of the research was to reflect how the principles of participation be most usefully applied in other contexts so that adults with Asperger's syndrome are more able to reflect on their experiences and express what they need from services. A combination of spatial analysis and the triads offer potential tools to aid the process of co-creation.

Although I will discuss the production of knowledge in Chapter Ten, I want to use the triads here to show that together with spatial analysis, they can aid in the application of the principles of participatory approaches in co-creating a research space. I discussed earlier Beresford's (2005, pp. 9-10) proposed two 'key and related lessons' that need to be addressed for inclusive research to 'work for everyone': *access* and



*support*. The Triad of Understanding provides a framework for discussing these 'lessons' at an individual or micro level and the spatial analysis framework at a structural or macro level.

It is only through mutual understanding that issues in relation to access and support can be addressed. In Chapter Four I cited Beresford's (2005, p. 10) definition of what support means in the context of inclusive research: '...people can expect to have whatever help, support, encouragement, information and skill development they may each need to contribute what they want to, how they want to'. Using this definition, support was available to all group members in the research space. We all developed our skills in working together and these evolved through our discussions of how to work together. Each member was a source of support for the others as well as a source of encouragement. Crucially, all members did contribute in exactly the way they wanted to. For future research settings, the Triad of Understanding could be used as a framework for exploration of support needs. Co-researchers in other contexts could work with the researcher to develop a greater sense of self understanding in the context of the research. Preliminary discussions of this nature, where self understanding of all group members is considered, set the context well for the principles of participation to follow. One area where this would have been useful in this research is in relation to the social model. The Triad of Understanding could have been used together with the social model, and the Triad of Misunderstanding with the 'medical' model.

In our research space, we addressed many issues of access, examples of which are the use of non-metaphorical language by all group members and the provision of an environment which allowed all group members to concentrate on the work, minimising distractions. The Triad of Understanding is a useful tool for promoting understanding between all parties. It could be used to frame discussions and to explore issues of access between researcher and co-researchers.

The spatial analysis framework outlined in Chapter Two provided a structure for planning the research as well as evaluating it. As I have demonstrated above, it addresses issues of power and control. Zarb's (1992) two principles of 'reciprocity' and 'empowerment' (1992) are addressed within the framework and Oliver's (1992) third principle of 'gain' is implicit in the question about how a space is experienced. When a research space is co-created with people with Asperger's syndrome, co-researchers are able to reflect on their own experience. This research has shown the benefit of discussions of understanding continuing throughout the research and not being confined to the initial stages.

#### **a) Principles of participation demonstrated in the co-production of research**

It is my contention that only when an enabling research space is co-created that co-production of research can take place. An enabling research space allows for the possibility of research to be co-produced. For adults with Asperger's syndrome, this research space has to be an autistic space where alternatives to a deficit model can be considered. It is important that the adults with Asperger's syndrome are able to express what they think and that this is understood by the neuro-typical people who support them. It is important that cultural differences are taken into account as well as the power dynamics. The principles of participatory research and participation apply in the same way to adults with Asperger's syndrome but the additional power issues of neuro-typical and autistic cultures also need to be addressed. This needs to be addressed throughout the co-production of the research.

In Chapter Four I listed the characteristics which I hoped our co-created autistic space would have. Although I applied the characteristics to the co-creation of a research space, they also form a useful framework for discussing the co-production of the research. Applied to research production, this list can be adapted to reflect the principles of participation, as below. It can be used in future research to enable adults with Asperger's syndrome to reflect on their experience and express what they need from services. Participatory research should therefore have the following characteristics:

- The research findings and dissemination should be consistent with the underpinning philosophy of the social model of disability.
- The research should explore ways of removing disabling barriers
- The research should address issues of power and how it can be shared
- Although control of the process of the research remains with the researcher, every effort is made to make and share all decisions with the co-researchers
- The researcher and the co-researchers work together on and agree the research design, data collection, data analysis and the dissemination of results
- The research process, findings and dissemination should be enabling to the co-researchers rather than comfortable for the researcher
- The researcher and co-researchers have a joint commitment to finding how to co-produce the research
- The researcher and co-researchers consider new ways of thinking
- The research findings should be presented in a positive way and to the benefit of other people with Asperger's syndrome or autism

This checklist can be applied to any participatory research. It captures the principles of participatory research discussed in the Literature Review. It also demonstrates how the co-creation of a research space has to precede co-production of research. It is only when such an enabling space is co-created as a disclosive space that co-production can take place. When such a space is co-created, the purpose of participation as change can be realised. This change has to begin in the research space. Such a disclosive space allows for the possibility of change. Research that is based on oppressive ways of working with people where they are regarded from a deficit model perspective will produce research (with findings consistent with that approach) which ignores the very foundations of good research, namely the accurate reportings of the contributions of the participants themselves.

## **Chapter Ten**

### **Discussion II**

### **Knowledge Creation**

In the last chapter I discussed the process of the research. In this chapter I will discuss the output, or new knowledge that has been created. I want to begin with a consideration of the phenomenological approach to the research and how this approach led to the formation of new knowledge. I will also discuss what the research has revealed about how people with Asperger's syndrome view themselves and how using their perspective has resulted in a different way of understanding Asperger's syndrome. I will end with a consideration of how thinking spatially has given insights into Asperger's syndrome.

#### **1. Phenomenology**

This research was informed by interpretative phenomenology. Phenomenology is concerned with trying to understand personal lived experiences and interpretative phenomenological analysis is concerned with exploring people's relatedness to phenomena (Smith, Flowers and Larkin, 2009). Within phenomenology, concepts have been developed which are helpful in thinking about this research. Husserl's concept of '*Auffassungssinn*' or 'grasping sense' refers to the interpretive component in intentional acts (Moran, 2000). As Moran explains (2000, p. 234), 'When we see something, we always see it as something and project a certain set of expectations upon it, expectations which are then fulfilled or exploded in subsequent perceptions'. Applied to this research, this concept relates to the perceptions of the adults with Asperger's syndrome who took part. The co-researchers, as already detailed, saw the difficulties they experienced as being due to their own 'deficits'. They expected to be misunderstood and to misunderstand others. As Katrina voiced at the conference, she expected our research to be another disappointing and difficult experience for her, as

this concurred with previous experience, but also it concurred with her view of Asperger's syndrome as a deficit. This was borne out by the data from the questionnaires-for example, one respondent stated that he realised he had no friends at school as a result of having Asperger's syndrome. The responses to question 5 of section C of the questionnaire are also telling. The question asked what improvements could be made to services to help them relate to people. Those that made suggestions made them about support in how to cope with stressful situations caused by not understanding the behaviour of other people, practical workshops to help people with Asperger's syndrome to be able to communicate with others as well as the opportunity to interact in groups. Although the question did lead to responses which focused on the 'needs' of the person with Asperger's syndrome, it is still significant that all of the suggestions were aimed at changing the person with Asperger's syndrome, not the world they engage with. The respondents had experienced difficulties in relating to people and expected this to continue. They thought that they needed support to change.

Another development in phenomenology helps in understanding this more. Heidegger linked Husserl's concept of *Auffassungssinn* with hermeneutics and wrote that experience 'is interpreting and encountering what has already been interpreted by ourselves and others' (Moran, 2000, p. 235). This act of interpreting is not necessarily verbalised but is evidenced in the way that people relate to things (Moran, 2000, p. 235). I also discussed Foucault's work on the duality of the 'Same' and 'Other' (Philo, 2004) and how people with Asperger's syndrome are 'othered' by society and also by themselves, as evidenced by the literature from authors with Asperger's syndrome (O'Neill, 1999; Sainsbury, 2009; Hoopman, 2013). People with Asperger's syndrome interpret the difficulties they experience in the light of their own experience, but this is first interpreted in the light of the discourse about Asperger's syndrome. They expect to fail in situations and believe this to be as a result of their own perceived deficits. Diagnosis is the tool by which people are identified as having Asperger's syndrome. It formalises the differences between people with Asperger's syndrome and neuro-

typical people. Molloy and Vasil (2004) considered that diagnosis is important as it often helps people with Asperger's syndrome make sense of their lives. This 'sense making' does influence the experience of the people who are diagnosed. For them, it explains what they cannot do (as well as what they can do well) but it also frames their experience as a deviation from what is expected, as being 'other', or 'out of step' with neuro-typical people.

Given the above, I wanted to understand the experience of people with Asperger's syndrome from their own perspective. This was problematic as everyone who has been diagnosed is already set on the path of understanding themselves and their 'condition' from a medical perspective. In my view, a participatory approach which did not address the issue of how experience is shaped would have given very different results. I was not neutral in the research process as I had a theoretical understanding that I wanted to bring to bear to the research. It was my conviction in relation to the social model of disability and its application to people with Asperger's syndrome that helped to shape the experience of the co-researchers. I cited Moran (2000, p. 234) above in relation to what is seen and perceived and expectations being 'then fulfilled or exploded in subsequent perceptions'. It was the introduction of the social model to the co-researchers and talking to them about their experience in the light of this that 'exploded' the previous deficit based understanding of their experience. My own views had of course in turn been influenced and 'exploded' by the writings of disabled writers such as Oliver (1992). What I had in fact done, was used the writings of disabled writers who made sense of their own experience through the lens of the social model of disability to offer a new lens to the co-researchers through which to see the world and understand their experience. This fits well with an 'existential hermeneutical' (Moran 2000) approach as it acknowledges the way experience is understood through interpretation. However, it goes a stage beyond such an approach as I purposely tried to replace one set of interpretations with another i.e. with an understanding of experience based on a medical model to one based on the social model. I then sought to work with the co-researchers to understand the experiences of

other people with Asperger's syndrome through the research tool design, data collection and data analysis. The experiences of the questionnaire respondents and focus group participants were understood through the interpretation of the co-researchers, through a new understanding of their differences to neuro-typical people. This influenced the knowledge formation and I will address this later in this chapter. Before I do this, I will discuss the findings of the research in relation to the literature concerning Asperger's syndrome.

## **2. Asperger's syndrome**

This duality of Asperger's syndrome and neuro-typical people is confirmed by the research. The research group was obviously formed on the basis of this separation so this duality set the context of the research. The co-researchers regarded it as very important that they and the participants in the different stages of research had an actual diagnosis of Asperger's syndrome. This is a common theme in the literature where the separation of people with autism or Asperger's syndrome and those without the condition, that is, neuro-typical people is common (Wing, 1981; Baron-Cohen, 2004; Attwood, 2007). People with Asperger's syndrome regard themselves as 'different' from neuro-typical people and neuro-typical people regard themselves as different to them (Lawson, 2001; Muggleton, 2012).

What the research has also confirmed is that the people with Asperger's syndrome included in the research do in fact regard themselves as different to neuro-typical people. They also believe themselves to live in a world where they feel the 'outsiders'. The research also shows that they do struggle to communicate with people who are neuro-typical and they often misunderstand them and misinterpret social situations. This all accords with the literature. The literature demonstrates how Asperger's syndrome has been medicalised and regarded as a deficit rather than a difference. Asperger (1991) referred to 'functional disturbance', 'personality disorder' and 'abnormal personality structure'. I have noted how Kanner and Eisberg (1956) suggested diagnostic criteria. Asperger and Kanner both wrote that the children they

observed were unable to communicate in effective ways and also did not have any motivation to communicate in a meaningful way with others. I discussed how Happé (1994) characterised Van Krevelen's work as demonstrating that a child with early infantile autism (Kanner's autism) 'lives in a world of his own' whereas the child with autistic psychopathy or Asperger's syndrome 'lives in our world in his own way' (Happé, 1994, p. 93). How this is then understood is key to how people with Asperger's syndrome are regarded and treated. If these differences are regarded as a deficit then 'treatment' of some description follows in the attempt to get them to fit into the neuro-typical world (Lovass, 1993). If people with Asperger's syndrome have developed in such a way which is outside 'normal development' then this presents professionals with the challenge of trying to understand and remedy this. As Kugler (1998) notes, for people with Asperger's syndrome 'social impairment' is the primary 'abnormality'. If these differences are indeed 'abnormalities' then remedial treatments again can be argued for. I detailed how the triad of impairment (Wing, 1991) had been proposed as a way of understanding people with autism, including those with Asperger's syndrome. The three impairments in this triad are deficits in social interaction, social communication and social imagination. The very name of this model for comprehending autism clearly places it as impairment based.

### **3. Viewing differences differently - knowledge formation**

This research has shown is that it is possible to agree with the description of the difficulties that people with Asperger's syndrome experience but to understand them very differently. The co-researchers and the participants detailed many examples of how they struggle to function in a world that they do not understand. What is new is how this is then understood. As discussed at the beginning of this chapter, a new understanding was possible due to the discussions about the social model of disability and the subsequent reframing of experience on the part of the co-researchers. As a result of this, rather than trying to change people with Asperger's syndrome so they can function in social situations and in communication, a new approach is proposed. The triads of understanding and misunderstanding were proposed as



acknowledgement of the misunderstandings that do happen between people who are neuro-typical and people with Asperger's syndrome. One example from the literature was Baron-Cohen's 'mindblindness' which attributes misunderstanding to an inability to perceive what other people are thinking (Baron-Cohen, 1997; Attwood, 2007). What is different is that these models emphasise joint responsibility. It is not for neuro-typical people to change people with Asperger's syndrome nor for people with Asperger's syndrome to change to be more like people who are neuro-typical. The research instead proposes a model of mutual responsibility. Acknowledged is the fact that it is difficult for people with Asperger's syndrome to understand the world of neuro-typical people but it is also acknowledged that it is equally difficult for neuro-typical people to understand people with Asperger's syndrome. It is when both understand each other that people with Asperger's syndrome can succeed in social interactions and in communication. A deficit model of understanding Asperger's syndrome is replaced by one that acknowledges mutual difficulties in understanding between people with Asperger's syndrome and neuro-typical people.

An application of phenomenology and hermeneutics can aid in thinking about the deficit based models of Asperger's syndrome. The word Λογος (Logos) is usually translated as 'word', but Heidegger translated it as 'discourse'. Heidegger returns to its etymology where the word means 'to gather up' into a synthesis or 'let something be seen' (Moran, 2000, p. 229). Moran (2000, p. 229) writes that discourse 'lets things be seen' and 'brings the matter out into the open, makes it manifest'. Moran explains that this is central to Heidegger's view of truth; 'truth' is about making manifest that which is hidden. Using this idea together with Foucault's assertion that people become subjects of documentation (Foucault, 1977a) and that power operates through knowledge (Foucault, 1998) provides an insight into how the deficit models of understanding Asperger's syndrome have had such profound impact. If 'truth' is about making what is hidden 'manifest', then the development of deficit models are based on what is already thought. Neuro-typical people experience people with Asperger's syndrome as being different from themselves. As explored in the Literature Review,

Kanner's (1946) and Asperger's (1991) categorisations of the children they saw was based on their understanding of what is 'normal'. As in Foucault's (1988 and 1989b) concept of 'Othering', children who do not behave in the way that conforms with what is regarded as 'normal' are Othered. The idea that children who do not conform are deviant in some way was 'made manifest' in the truth or discourse about Asperger's syndrome. Seen in this way, the deficit based models are a reflection of the experience of neuro-typical people and did not take into account the experience of the people who were subject to the discourse. Foucault's assertion that power operates through knowledge adds additional depth to this analysis. People with Asperger's syndrome are subject to the exercise of power through being seen as inferior to neuro-typical people and expected to conform to neuro-typical behaviour, as evidenced by Willey in the title of his book, 'Pretending to be normal' (Willey, 1999) and Williams in her account of trying to conform to society's expectations (Williams, 1996). What this research aimed to do was to arrive at a narrative based on the experiences of people with Asperger's syndrome and make a new 'Logos' apparent.

The research aimed to discover what support people with Asperger's syndrome needed from services. What we discovered was that it was in the areas of the need to understand and to be understood that people with Asperger's syndrome wanted to be supported. This is not another deficit based model of understanding Asperger's syndrome. It is instead a way of understanding in what areas people need to be supported. The difference is that rather than try to change people with Asperger's syndrome, it requires both parties to understand each other. People with Asperger's syndrome are not seen from a deficit model. Instead, they are seen as having different ways of understanding communication and social situations from people who are neuro-typical. The two ways of understanding mean that both people with Asperger's syndrome and neuro-typical people need to be supported in understanding the other. It does not put these different ways of understanding on a hierarchy with one being 'normal' and the other deficient or abnormal. They are simply different.

Often training about autism or Asperger's syndrome is called 'awareness training'. This usually takes the form of explaining how people with autism or Asperger's syndrome have 'problems' in communication and social interactions (NCC, 2013). Such training forms the basis from which 'autistic spectrum disorder' can be understood by professionals and the basis of how they work with people with Asperger's syndrome. It separates neuro-typical people and people with Asperger's syndrome in two ways. Firstly, it is based on a deficit model of autism, where people with autism are portrayed as not functioning as well as people who are neuro-typical. Secondly, it elevates some neuro-typical people to the realm of 'experts'. These experts can impart what is 'wrong' with people with autism and suggest strategies or interventions to work with them. This research however highlighted the need for mutual understanding as well as self understanding.

The triads of understanding and misunderstanding are based on an individual understanding of Asperger's syndrome rather than a 'one size fits all' approach which is suggested by models such as the triad of impairments. Heidegger wrote that discourse can be passed along from person to person and can get distorted as it does so (Moran, 2000, p. 230). Although the triad of impairment (Wing, 1996) was originally intended to describe the characteristics of autism and Asperger's syndrome, it was my experience as a practitioner that it became a kind of short-hand for understanding the person in a very simplistic way. Rather than see it as a tool to understand how people with Asperger's syndrome think differently to neuro-typical people, but are still individuals, it is my experience that it is used by some to understand the whole person. This approach is over simplistic and ultimately unhelpful and discriminatory. The co-researchers were completely different in their individual strengths and in the specific difficulties they experienced in their social interactions and communication. This was replicated in the experiences of the participants. The triads of understanding and misunderstanding are proposed as ways of focusing attention on individuals with Asperger's syndrome and the neuro-typical people they interact with. Each person with Asperger's syndrome is different but they all experience difficulty in

understanding themselves and others. Neuro-typical people also experience difficulty in understanding people with Asperger's syndrome. The support that people with Asperger's syndrome need, according to this research is to be supported to understand themselves and other people. This could be in relation to a specific situation where misunderstanding occurred. The Triad of Misunderstanding can be used to discuss the situation in relation to gaining self understanding and understanding about the other person or people involved. The 'other person' also needs to be supported to understand the person with Asperger's syndrome. As discussed in the previous chapter, the co-researchers stated that people with Asperger's syndrome have individual identities and it is their common experience that unites them. The triads of understanding and misunderstanding reflect this; they were developed to recognise this common experience but to be applied to people as individuals.

Bogdashina (2006) proposes that autism be viewed as a 'different way of being' and that behaviours could be viewed more positively if viewed from that perspective. This research takes Bogdashina's assertion a stage further. People with Asperger's syndrome have common experiences but are all individuals; there is not one 'different way of being', there are many. It is the responsibility of neuro-typical people and people with Asperger's syndrome alike to try to understand how each perceives. It is not just a matter of the behaviour and way of thinking of people with Asperger's syndrome that needs to be understood and explained but also that of neuro-typical people.

#### **4. The triads of understanding and misunderstanding**

As already stated, neither I nor the co-researchers are denying that people with Asperger's syndrome experience difficulties in the areas of social communication, social interaction and social imagination as defined by neuro-typical experts (Wing, 1996; Attwood, 2007). People with Asperger's syndrome experience these difficulties because they are in a minority and there are expectations that they engage in interactions and communication that they do not find easy. They do not find this easy

because the agenda is set and determined entirely by neuro-typical people. The research has shown that people with Asperger's syndrome do want a better understanding of social situations and would like support to help with this. The emphasis in this research on mutual understanding challenges the perception that people with Asperger's syndrome necessarily find it difficult to interact and communicate and instead frames the difficulty as mutually arising. It should not be a case of people with Asperger's syndrome being supported to fit into a world that does not understand them, but of neuro-typical people and people with Asperger's syndrome being supported to understand each other. The three corners of the Triad of Understanding identify the areas in which support is needed. These areas were clearly identified in the data and by the co-researchers as we analysed and discussed the data. I will now discuss each of these areas in more depth.

#### **a) Me understanding myself**

The topic that engaged the co-researchers and myself the most was how each co-researcher understood themselves. Included in this was self acceptance. The three co-researchers had different experiences of being diagnosed with Asperger's syndrome and had responded differently from each other to their diagnosis. For all three it explained to them why they struggled in their lives and particularly in their relationships. Two of the co-researchers were comfortable with their diagnosis and had accepted themselves as people with Asperger's syndrome. However, for one co-researcher she understood her diagnosis to mean that she could never have a successful life as she was unable to communicate effectively or succeed in social situations. As I detailed in earlier chapters, the group summarised the theme 'me understanding myself' as:

Information about Asperger's syndrome, other people with Asperger's syndrome's experience and explanations from those around me help me in understanding myself. A complete picture of myself helps me to develop coping strategies that in turn help me deal with life.

It is difficult for individuals with Asperger's syndrome to form positive views of themselves on their own. They grow up in a world where they are regarded from a deficit model and this is formalised and medicalised through their diagnoses. They learn two things about themselves, firstly that they find communicating and interacting with people difficult and secondly, and upon diagnosis that this is because they have Asperger's syndrome. The theme of 'me understanding myself' shows the importance for people with Asperger's syndrome of understanding how neuro typical people are different to them and why their differences mean that they find communication and social interactions difficult. It is only when they understand how they are different and why this presents them with problems in a world that is organised for and by neuro-typical people that they can begin to develop ways of coping in that world. It is notable that the summary of this theme states that other people with Asperger's syndrome can help with self understanding and I certainly witnessed that this happened in our group sessions. As one co-researcher related an experience where they had not understood why they had reacted or behaved in a particular way, another would also recount a similar experience and together they would build an understanding of why this had happened. The literature confirms the need for self understanding and also for this being shared with other people to aid them in understanding the person with Asperger's syndrome. Sinclair (1993, p. 2), a writer with autism wrote: 'It takes more work to communicate with someone whose native language isn't the same as yours. And autism goes deeper than language and culture; autistic people are 'foreigners' in any society'. Sinclair was aiming this at parents of a child with autism. He goes on to write that parents should give up their assumptions about 'shared meanings' and let their child teach them their language and 'guide you a little way into his world'. Shared meanings should not be assumed, but should be aimed at being based on the self understanding of the person with Asperger's syndrome and this being shared with others.

#### **b) Me understanding others**

The research has shown that people with Asperger's syndrome spend a lot of time and emotional effort struggling with what the second theme summarises as 'me understanding others'. What was apparent to me, particularly in the sessions with the co-researchers was the unequal amount of effort they put into trying to understand neuro-typical people. This is in contrast to the amount of time that most neuro-typical people will spend trying to understand people with Asperger's syndrome. This theme was summarised by the group:

It is important to understand other people's language and behaviours. It helps me to understand what my role is and I cope by adapting my behaviour to improve my relationships.

By 'others' is meant people who are neuro-typical. The summary of the theme does accord with the triad of impairment in that it agrees where difficulties are experienced. As the summary indicates, people with Asperger's syndrome want to understand other people in order that they can better function in society. They can cope better in situations if they understand why people say some of the things that they do, for example some jokes and use of metaphors. They also cope better if they understand how people use language in ways which are not literal. The co-researchers often discussed examples of where a neuro-typical person had said something but did not actually mean it. They found this confusing, for example when the neuro typical person was just being polite rather than honest about their opinions. This theme highlights the support that people with Asperger's syndrome need in understanding behaviour and language which mystifies them as there seem to be many hidden social rules.

### **c) Others understanding me**

The third theme in the Triad of Understanding is 'others understanding me'. This theme is both present and absent in the triad of impairment. It is present in that the point of the triad of impairment is to understand people with autism and Asperger's syndrome. It is also present in that it offers to neuro-typical people (as well as people with autism and Asperger's syndrome) a model which categorises the difficulties that are experienced, but from a deficit perspective. It is absent in that the triad of

impairment does not consider the role of neuro-typical people-it is not designed to do so. It presents a model of understanding which defines difference as deficit and presents that as the context in which to understand people with autism and Asperger's syndrome. The theme summary is:

It is important that others understand me. When people understand me, they can explain things to me and then I can cope a bit better. I can help people to understand me by explaining things from my perspective, which overall improves my relationships.

The summary, like the other two is linked to how people with Asperger's syndrome cope in society. It acknowledges a joint responsibility as neuro-typical people can only properly support the person with Asperger's syndrome when they understand them. The person with Asperger's syndrome can help with this by explaining to them how they understand situations differently. Bogdashina (2005), a neuro typical writer has written that if neuro-typical people want to understand people with autism, they need to either learn their language, or find an interpreter. She states:

If they try and interpret our ways of functioning, why can't we do the same? Since imagination is one of the areas in which people with autism have difficulty, it should be easier for us to imagine what it is like to experience the world in an 'autistic way' then the other way round (Bogdashina, 2005, p. 16).

Once we have understood people with autism, according to Bogdashina, neuro-typical people can then offer them support with their 'difficulties'. This research suggests that the person themselves can act as an 'interpreter', once they understand themselves. It also indicates that there can be a role for a 'third person' who is neuro-typical to act as an interpreter.



## **5. Re-thinking environmental factors and Asperger's syndrome**

The Literature Review discussed the environmental theories of autism of Bettelheim and Kanner (Whitman, 2004) and how these have largely been replaced by biological theories. I noted how this shift had given rise to a search for treatments rather than looking to the environment for the causes. This research has not attempted to discover the origins or causes of Asperger's syndrome. However, it does highlight the importance of environment but as somewhere where either understanding or misunderstanding takes place rather than where autism or Asperger's syndrome is caused. This research has been based on an acceptance of difference and the social model of disability (which is considered below) so the 'causes' of any differences were not an appropriate area for investigation. It is interesting that the original environmental theories led to parents, mainly mothers being blamed for the autism of their child. This research does not seek to allocate blame but to consider possibilities for mutual understanding. Bogdashina (2006), as seen in the Literature Review wrote that people with autism can flourish if the conditions are right. She wrote about the role of the environment in causing difficulties for people with autism. The findings from this research concord with Bogdashina's assertions and has proposed a model of understanding that can be used to support people with Asperger's syndrome. If the model is used to help people with Asperger's syndrome and neuro-typical people to focus on enhancing understanding then a more enabling environment will result for all parties.

## **6. Insights from thinking spatially**

### **a) People with Asperger's syndrome, their space and the 'gaze'**

From a Foucauldian analysis, people with Asperger's syndrome are characterised as belonging to a different world or space and it is this that enables the prescription of treatments. In the Literature Review, I discussed the use of the 'gaze' and how it is through the use of the gaze that discourse is formulated. Foucault (1989a and 1989b) discusses the examples of the sick, prisoners and the mentally ill to show how

discourse is formed through the gaze of professionals. This discourse is then used to control people. This view of power and use of spatial analysis was very influential to my own approach to this research. What this analysis does not promote is for the gaze to be applied the other way round. One of the things that this research has achieved is to make neuro-typical people subject to the gaze rather than people with Asperger's syndrome. A lot of discussion with the co-researchers concerned how neuro-typical people think and behave. The research space in which the group worked was one in which there were more people with Asperger's syndrome than neuro-typical people (unless artificially created for a specific purpose this very rarely happens in society). I have stated that my aim was to 'co-create with them a research space in which they were not subjected to a gaze, one in which I learn from them and they from me rather than one in which I operate from the discourse of Asperger's syndrome as deficit.' I had not anticipated that the gaze could or would be reversed and that the co-researchers would discuss neuro-typical people with a level of mystification commensurate with that displayed by neuro-typical people when discussing those with Asperger's syndrome. I was interested to read of work that discussed a reversal of the gaze in relation to the male gaze (Goddard, 2000) where the female gaze was used to understand how masculinity is constructed. This research was not concerned with how people with Asperger's syndrome construct or understand what it is to be neuro-typical, although this would be a very interesting area to explore in future research. The way in which the gaze of the co-researchers is different from the gaze that is cast upon them is that the co-researchers were not concerned with creating a discourse based on a deficit model. Instead they were concerned to understand how neuro-typical people think and behave. The motivation is very different; the gaze of the co-researchers was an attempt to understand in order for them to be able to 'cope' with living in the world of neuro-typical people.

#### **b) Discursive space allowing for new possibilities of understanding**

The co-researchers and I used the research space we co-created as a discursive space where the dominant narrative about Asperger's syndrome could be put to one side

and different possibilities considered. I discussed the concept of a discursive space based on Dreyfus' interpretation of Foucault's writing in Chapter Two (Dreyfus, 2004). Dreyfus talks about a discursive space as a 'local clearing'. The data analysis led to the formation of the triads of understanding and misunderstanding. Rather than choose to look at individual services, which was a choice that could have been made from the data we received, the group chose to organise the data in terms of general themes. As discussed in the methodology chapter, it was a joint decision to put the three main themes into a triad and to name them as we did. Although it was my suggestion that we do this, it was possible because we had purposely co-created a space in which we wanted to put the dominant discourse to one side. The co-researchers were very enthusiastic about this proposal as they thought it captured the group's philosophy as well as summarised the ideas we saw in the data.

The co-researchers want the triads of understanding and misunderstanding to provide the structure for discussing the differences between people with Asperger's syndrome and neuro-typical people. The triads are a tool to help with this. People with Asperger's syndrome recognise that they inhabit a world dominated by neuro-typical people and that they need to understand this world in order to 'cope'. I cited Lawson (2001, p. 17) in the Literature Review, Chapter Two as saying: 'For many of us with this diagnosis, we experience our disability in a neuro-typical world as anything but mild!'

Lawson was referring to the view of some that Asperger's syndrome is a 'mild' form of autism. She is maintaining that her experience does not suggest this. Asperger's syndrome is always experienced in the neuro-typical world as disabling. The Triad of Understanding is how the co-researchers chose to represent what they found in the data from other people with Asperger's syndrome. There is a recognition here of being 'Other', of being unable to understand the neuro-typical world without support. There is also recognition that it is just as difficult for neuro-typical people to understand people with Asperger's syndrome. When people with Asperger's syndrome function within a neuro-typical world, differences need to be understood by both parties. As

detailed in Chapter Two, Sinclair (2010) discussed three types of spaces- autistic spaces, shared autistic spaces and neuro-typical spaces. He writes of shared autistic spaces rather than shared neuro-typical spaces because it is the experience of people with Asperger's syndrome that neuro-typical spaces are not shared. The research has not led to a call for society to operate in a shared autistic space but for people with Asperger's syndrome and neuro-typical people to co-exist in the same space with a better understanding of each other. There is an implicit recognition here that the neuro-typical world is the space in which people with Asperger's syndrome have to live. The word that the group chose to describe how they have to live in this neuro-typical world was 'cope'. What they want from services or from support is to enable them to 'cope' in this neuro-typical space, which they find so alien. Having learnt to cope, they might then go on to 'thrive', but that was not an expectation that was expressed by the co-researchers.

### **c) Lessons from thinking spatially**

One of the lessons we learnt was in relation to the importance of co-creating autistic spaces beyond our research space. When planning the conference, the co-researchers and I had spent a lot of time discussing how to ensure that we were able to talk to a large audience about our findings. We had considered ensuring that the conference was opened by the co-researchers rather than me. We had also discussed how they were going to talk about what they had done and learnt so that their role in the research was fully acknowledged. We scripted the whole conference and practiced it many times, including details such as when to stand up and when to pass the microphone to someone else. We also practiced in the room where we held the conference. We did this to make the conference as predictable as possible and give the co-researchers as much control as possible. We tried to make the conference an autistic space for the co-researchers. What we failed to do was to consider the attendees who also had Asperger's syndrome. The only negative feedback we had from the conference was from some of the attendees who had Asperger's syndrome. They were not negative about the findings but about how we had conducted the

conference. We had created an autistic space where the needs of the co-researchers were met, but within a larger neuro-typical space. The attendees with Asperger's syndrome were overwhelmed by the nature of the group activities and being expected to talk to people they did not know. If we were to conduct another conference to which people with Asperger's syndrome attended, we would consider how to do this differently and perhaps use some of the strategies used in the 'Autoscape' conference as discussed previously. What we unwittingly created was a collision of a neuro-typical space and an autistic space. It was 'comfortable' for the co-researchers, but not for the other adults with Asperger's syndrome.

The lessons learnt from this part of the research demonstrate very well the difficulty there is in not only understanding but applying an understanding of difference to practice. In our concern to ensure that the co-researchers were 'comfortable' and that the space we co-created was 'autistic friendly' to them, we lost sight of the possibility of attendees with Asperger's syndrome being presented with difficulties. We wanted to 'turn round' a space where service users are usually controlled and make it service users' own space (Petrie and Moss, 2002). We succeeded in some areas but failed to make this wider than for the group of co-researchers. In protecting the research space for the co-researchers it seems that we inadvertently disadvantaged other adults with Asperger's syndrome.

#### **d) Space, identity and Asperger's syndrome**

The findings demonstrate how the participants with Asperger's syndrome do not have a common sense of identity, except in that of being 'outsiders'. As the data has shown, participants disagreed as to whether Asperger's syndrome is a disability or not and many were unwilling to share their diagnosis with other people for fear of being discriminated against. The sentiments expressed by the participants concur with the theme identified in the literature of being 'alien' or 'outsiders' (O'Neill, 1999; Miller, 2003; Sainsbury, 2009). The Triad of Understanding is proposed as a tool to support people with Asperger's syndrome due to the fact that they feel excluded from the

knowledge of how to 'navigate' the neuro-typical world, to address this feeling of alienation. In Chapter Three I detailed how Campbell and Oliver (1996) discussed that disabled people struggled to see the world as anything other than one space for non-disabled people and one for them. For disabled people this led to a sense of a separate identity. In this research, as discussed in the previous chapter, the co-researchers understood their identities as being individually defined. For them, it is their experience of living in a neuro-typical world that they have in common. Initially I was surprised by this distinction. I have come to understand this in the context of how people with Asperger's syndrome are diagnosed. The co-researchers had opportunities for reflection and sense-making that the other participants did not by virtue of being in the group. They were able to consider the data and reflect on the lack of a sense of common identity among the participants. They had the opportunity to review their own experience through the lens of the social model of disability. For the co-researchers, it is the common experience of people with Asperger's syndrome of misunderstanding and being misunderstood that unites them but they were also concerned to be seen as individuals. While disabled people in the disabled people's movement had to assert their common identity to challenge dominant ideologies, this research suggests that the people with Asperger's syndrome who were the co-researchers want to assert their individuality.

In this and the previous chapter, I have discussed the process and outcomes of this research. I have shown how the two are inextricably linked. The outcomes would not have occurred if the process had not been one of co-creation of our research space. The literature informed the way the research was conducted and in turn this has led to new knowledge being generated based on the experience of people with Asperger's syndrome.

## **Chapter Eleven**

### **Evaluation and Conclusion**

I will reflect on the challenges and limitations of this research before considering its significance. I will reflect on how the research provides a challenge to previous 'knowledge' and its wider implications. I will conclude with implications for service provision in relation to the research question: 'What support do adults with Asperger's syndrome want?' and make suggestions for future research.

#### **1. Challenges and limitations**

##### **a) Limitations of the process**

The challenges to me in this research were significant. I wanted to discover if research based on the social model of disability and applied to adults with Asperger's syndrome would work. I was convinced from my own experience and from my reading that a participatory approach to research could work with adults with Asperger's syndrome. I had been a confident social work practitioner and I knew that I was good at forming working relationships with adults with Asperger's syndrome but that had been in a very different role to that of researcher. I was concerned that I might not adjust well to a different task.

There were also practical challenges to the research including ill health of one of the co-researchers and the postponement of sessions to wait for that person to recover enough to rejoin the group. We also encountered poor weather, with heavy snow meaning that some sessions were cancelled. This made the sessions not as predictable as I would have liked, but the co-researchers coped well with this. To try to reassure them, I emailed them regularly and explained all difficulties. With one co-researcher, I also communicated with her family (with her permission) so they were able to support her when the sessions had to be cancelled.

A limitation of this research lay in the number of people who took part. Although, as described above every effort was made to include every adult with Asperger's

syndrome living in the county in which we conducted the research, a much smaller number actually took part. The method of analysing the data, line by line as a group was however very time consuming and took many months with the amount of data that we had. A limitation of working in this way is that if a much larger amount of data was produced, it would be an even bigger task for a similar group.

This research was conducted on the basis of the identity of having Asperger's syndrome alone. Although we did ask for the gender, race and age group of the respondents to the questionnaire, we did not use this data. The identity of having Asperger's syndrome was what concerned all the co-researchers rather than any other identity. The co-researchers were all white, as were most, but not all of the participants in the questionnaires and focus groups. It could be argued that the research did not consider culture or race. Although this would be a valid criticism, the concern of the research was with co-creating a research space that was sympathetic to people with Asperger's syndrome. If we had co-researchers who were of other ethnic origins, then we would have discussed any additional considerations that were necessary. We also did not consider gender, although we did ask respondents to the questionnaire to declare their gender. We did not consider sexuality at all and did not ask respondents to declare this.

Two other limitations of the research are linked. There were times, as documented above, where I steered the direction of the research. If I had not done so, the research may have been somewhat different. The most significant example was the suggestion that we conceptualised the three main themes from the data in the form of a diagram representing the Triad of Understanding. Although this was agreed with enthusiasm by the co-researchers, this did affect to a great degree how the research progressed. Two of the co-researchers were previously aware of the triad of impairment and I explained it to the other. This could be seen as a strength as it was done within the principles of co-produced research. However, it was not consistent with my phenomenological



approach as I had a role in influencing how the co-researchers came to understand their own experience as well as the data that was produced.

The other related limitation is how the co-researchers influenced the research process. An example of this is where some data was disregarded as it was not thought to answer the questionnaire questions precisely. This was true to my phenomenological approach, but this may have resulted in the loss of relevant information.

The first aim of this research as stated in the Introduction was to use a participatory approach to explore how adults with Asperger's syndrome make sense of their experience of living in a neuro-typical world. The co-researchers and I did this through exploring the question of what support people with Asperger's syndrome would like to receive. One limitation of this was that the exploration was framed within the assumption that people with Asperger's syndrome do need support. I did not explore whether people with Asperger's syndrome could live without support but assumed that it was necessary. In this context I am a part of a neuro-typical society prone to separating people out as being different. However, the Triad of Understanding is an attempt to frame the support needs of people with Asperger's syndrome in such a way that it concentrates on differences of understanding rather than deficits.

#### **b) Limitations of the theory we produced**

An area of omission from the Triad of Understanding is 'me understanding myself' from the point of view of the neuro-typical person. There is an assumption that this only applies to the person with Asperger's syndrome so assumes that neuro-typical people understand themselves. This omission reminds me of white students who find it difficult to reflect on their identity as they live in a predominantly white society. It is black students who are able to reflect more easily on their identity. It is likely that most white people have not considered what it is to be white as they have not had to. In the same way, neuro-typical people will not necessarily have a good understanding of why they act or think as they do. They do not necessarily have the insight needed to explain to someone with Asperger's syndrome about their own behaviour. Having said this,

the way the research was conducted does remain true to the stated aim. It was to determine how adults with Asperger's syndrome make sense of their experience, but it is nevertheless an omission.

The context of the research is important to remember here as it was concerned with services and support. As discussed earlier, very different findings might have resulted if the research aim had been different. If the research had focused on how people with Asperger's syndrome wanted to change society so they were included more, very different findings might have resulted. Whilst this is an imponderable, it is an important point. I formed the research group and I am a registered social worker. I am trained and experienced in understanding people according to their presenting needs and how those needs can be met. While I endeavour to work from a social model perspective, what I thought was a good area to research might have been very different to what a group of people with Asperger's syndrome might have chosen. Whilst I did everything I could think of to work in an enabling way, I have to acknowledge the power that I had as the researcher that formed the group. The focus of the research was on the individual experiences of people with Asperger's syndrome rather than their collective experience. It was therefore very different from the agenda of the disabled people's movement as it was not focused on political action but on the experiences of individuals and how these could be improved at that level, at the level of individual support. This point links very well to the views expressed by Finklestein (quoted in Campbell and Oliver, 1996) that it is important that disabled people form groups themselves and invite non-disabled people to join them once they are established or they will become oppressed groups. It was of course impossible for this to happen with this group. Processes of ethical approval and planning had to precede the group's formation.

I discussed in Chapter Three my resolve to try to understand the culture of the co-researchers and be respectful of it rather than impose a neuro-typical culture on the group. I have discussed the idea of a co-created research space and will return to this

when I discuss participatory research below. Noteworthy here is the tension highlighted in the literature of the negative influence that the inclusion of non-disabled people can have on groups of disabled people. I wished to understand the culture of the co-researchers so this knowledge could inform how we co-created our research space. I acknowledge the power that I exerted in setting the agenda for the research even if after that I did all that I could to work together with the co-researchers.

## **2. Knowledge explosions**

I have already quoted Moran (2000, p. 234) as writing: 'When we see something, we always see it as something and project a certain set of expectations upon it, expectations which are then fulfilled or exploded in subsequent perceptions'. It is in the light of this 'exploding' that I want to frame my conclusion. I will discuss how perceptions of people with Asperger's syndrome have been exploded by this research. I will discuss how the perceptions of the co-researchers and my own have been exploded and how this has resulted in a deficit model of autism being exploded. I will discuss how these 'explosions' have wider implications or 'shock waves', to continue the metaphor. I will use the centrality of the social model of disability in this research to demonstrate how doubt has been shed on previously held positions.

### **a) What people with Asperger's syndrome can achieve**

This research has demonstrated what people with Asperger's syndrome can achieve, given the 'right' environment. It set out to ascertain their experience of living in a neuro-typical world and how their experience could inform the way they are supported. There is a wealth of literature about Asperger's syndrome as well as literature written by people with Asperger's syndrome. However, at the commencement of my research I could not find any examples of literature which outlined research where adults with Asperger's syndrome were also participants, let alone co-researchers. Another area where there was a gap in the literature was in relation to applications of the social model of disability to people with autism and Asperger's syndrome. Publications by people with Asperger's syndrome were written

by individuals who tended to write of their experiences of living in a neuro-typical world. I was not aware of any examples of literature where the collective views of people with Asperger's syndrome were presented. Another gap in the literature was in relation to people with Asperger's syndrome working together to explore their experiences. Coupled with my experience as a social work practitioner of the difficulties that adults with Asperger's syndrome have in relation to gaining support which meets their needs, these gaps in the literature led me to want to explore what could be achieved. I wanted to explore how adults with Asperger's syndrome would work in a group with me and how they would use their experience to inform the research process and findings.

This study is important as it was the first example that I know of where participatory research has been attempted with adults with Asperger's syndrome as co-researchers. It is also the first study that I know of where a phenomenological approach has been undertaken to determine the experience of people with Asperger's syndrome and to use other adults with Asperger's syndrome as co-researchers to shape the research and interpret the findings in the light of their own experience.

#### **b) The social model of disability**

In the Introduction, I described my motivation for conducting this research. As a social work practitioner I had pondered how people with Asperger's syndrome should be best supported. I can now see that my understanding of Asperger's syndrome was rooted in a particular way of thinking that has been subsequently challenged or 'exploded' by our research. It had not occurred to me that neuro-typical people also need support. The need to understand the 'other' is a mutual need and it is only when mutual understanding occurs that successful communication can take place. The social model of disability had presented me with the challenge to separate impairment and disabling barriers (Oliver, 2009) but it had not presented me with the challenge to think about how I was impaired in any way. It had not led me to think that people who are neuro-typical have a lack of understanding. Although I see this as obvious now, at

the beginning of my research I would not have framed my understanding in that way. The social model propounds that disabling barriers are produced through how society is organised, which is primarily for non-disabled people to the exclusion and disadvantage of disabled people (Oliver, 2009). The model is concerned with providing an explanation for the discrimination experienced by disabled people. It is not concerned with the experience of non-disabled people. What this research has shown is that there is a need for mutual understanding, that there is a deficit in the understanding of neuro-typical people of people with Asperger's syndrome and vice versa. However, this understanding has come from an application of the social model to the research and by using of the experience of the co-researchers and the other participants with Asperger's syndrome.

In Chapter Three, I also cited some of the criticisms of the social model and detailed the cultural model and the relational models of disability, both developed outside the UK (Goodley, 2011). Neither of these models uses the distinction of impairment and disability and instead examine how disability is constructed. Both of these models can offer insights to this research. The cultural model offers a different explanation to that of the social model to why disabled people experience discrimination. It highlights how disability is understood through cultural practices. The findings show that there is a need for mutual understanding. If this mutual understanding is realised then it seems reasonable that cultural practices would change as a result. Current cultural practices are dominant within neuro-typical spaces. The concept of 'disabling barriers' from the social model explains one aspect of the experience of disability, namely, how disabled people are excluded from society. The concept of cultural practices constructing disability explains another aspect, namely, how the representation of disabled people reinforces normalcy. The relational model offers different insights. It proposes the 'mismatch' between the environment and the disabled person rather than the environment having a barrier as such. It calls for a change in the environment rather than the removal of disabling barriers. The findings have indeed shown that the 'impairment' experienced by people with Asperger's syndrome is situational, as the

relational model proposes (Goodley, 2011, p. 17). When people with Asperger's syndrome are in an autistic space, they do not experience their different way of thinking as an impairment; when they are in a neuro-typical space, they do. Although this research was based on the principles of the social model of disability, the relational model does have resonance. A neuro-typical space has to be changed to be an autistic space or at least to be compatible with an autistic space to allow for mutual understanding to take place.

### **c) Participatory research and the social model of disability**

This research has demonstrated that participatory research can be conducted with co-researchers who have Asperger's syndrome. It has shown that they are able to work well in a group where their Asperger's syndrome is understood and where group processes take account of this. It has shown that it is possible to conduct research that is based on an understanding of the social model of disability and produce research that distinguishes between 'impairment' and 'disability'.

In this research we equated 'impairment' with 'difference' and 'disability' with the way people with Asperger's syndrome are misunderstood and treated. In the Literature Review I cited Shakespeare (2006, p. 37) as writing: 'In fact, I would argue that any qualitative research with disabled people will inevitably reveal the difficulty of distinguishing impairment and disability'. Rather than show what Shakespeare asserts, which is the difficulty in distinguishing between the two, this research shows the importance of the difference. It is the separation of the way that people with Asperger's think with how they are misunderstood that has resulted in a model based on mutual understanding between people with Asperger's syndrome and neuro-typical people. If their 'disability', or how they are misunderstood is thought to be an inevitable 'effect' of their 'impairment' or different way of thinking, then it is people with Asperger's syndrome who have to change to fit in with neuro-typical people. If, however, the misunderstanding is seen as mutual, on the part of neuro-typical people and people with Asperger's syndrome, then there is a need for understanding to be

enhanced for both. I also cited Shakespeare in my Literature Review as stating: 'The social model of disability which has successfully inspired generations of activists has largely failed to produce good empirical research, because it relies on an overly narrow and flawed conception of disability' (Shakespeare, 2006, p. 9). I would argue that this research has shown Shakespeare's assertion to be mistaken. As discussed throughout, this research was based on the social model and the conception of disability that it proposes. In fact, the research would have been very different without it and I would argue would have been unable to have produced the results that it did in terms of enabling processes or findings. It was the very adoption of the social model of disability that freed myself and the co-researchers from a conventional way of thinking about Asperger's syndrome and allowed us to think differently. It was the social model that gave us the framework of thinking to develop our 'disclosive' (Dreyfus, 2004) and 'interrupted space' (Bolzan and Gale, 2011) which 'provides the opportunity for social actors to experience something different, something outside of their usual daily routine, and make meaning of it' (Bolzan and Gale, 2011, p. 505). For the co-researchers, 'something different' was being able to experience a metaphorical space which was an autistic space, an enabling space. For me, it was being able to experience a space where I was not dominant as a neuro-typical professional. I was not trying to assess or change the behaviour of the co-researchers, but rather, I was learning and working with them. This was only possible as we used the social model as our basis. It changed the perceptions of the co-researchers and although I was already convinced of its merits prior to starting the research, I continued to learn from its application throughout. As a result of having an interrupted space, we developed a disclosive space where the possibility of change is allowed for.

#### **d) Participatory, emancipatory and co-produced research**

Nind (2014, p. 73) discusses one of the criticisms of some participatory research as 'merely tinkering at the edges rather than transforming the social relations of research production' when compared to emancipatory research. Although, as stated in the Literature Review, there has been research which has been called 'participatory' that has transformed the social relations of research production (Browne et al, 2012;

Fleming, 2012), as Nind states, this is not always the case. As argued throughout, this research has achieved this aim and the co-researchers have had full involvement throughout. I have written an article (Martin, 2014), exploring whether this research can be regarded as emancipatory despite my involvement as a non-disabled researcher. In it I cite Johnson (2009) who allows for the original idea to come from a non-disabled researcher instead of a disabled person or organisation and for it still be emancipatory, providing it is 'owned' by the disabled co-researchers. The research has indeed been 'owned' by the co-researchers in many senses and the article we have co-written (Martin, et al, 2014, p. 78) which explores how we worked together as a group evidences this. One of the more powerful messages from this article is: 'Group members believe that it is their Asperger's syndrome that has made their group successful. It is successful *because* they have Asperger's syndrome, not *in spite* of it'. The research is 'owned' by the co-researchers to the extent that they call it 'successful' but more importantly than that, they have the belief that it is *because* of them having Asperger's syndrome that it was successful. This does not mean that they were merely needed for the study as they have Asperger's syndrome, but much more than that; their *attributes* as people with Asperger's syndrome contributed to its success. I would argue that this is a triumph for the application of the social model of disability. It certainly achieves Zarb's (1992) two principles of 'empowerment' and 'reciprocity' as distinguishing features of emancipatory research. It also achieves Oliver's (1992) third principle of 'gain' for the disabled co-researchers as a new sense of achievement and a more positive sense of identity resulted from taking part in the research. As noted in the Literature Review, the importance of the social model of disability for emancipatory research is that discussions of disabled people's experiences are framed within the context of a disabling society (Barnes, 2003, p. 10).

As the non-disabled researcher, I had a role in assisting the co-researchers in gaining an understanding of the social model of disability and we explored together how we could apply it to people with Asperger's syndrome. There was no literature that I was aware of to help with this particular application. This meant that we used the



experience of the co-researchers to discuss how the social model applied to them. The centrality of their own experience and the opportunity to discuss their experience together added to the richness of the research but also meant that the process had benefits for each co-researcher. I cited Durose et al (2012, p. 6) in the Literature Review as writing that in a 'co-created research space', 'interactive knowledge' is developed which rests on developing a 'shared thought style'. It was through the interpretation of the experience of the participants and co-researchers via the coding of our data that a common understanding was built. This common understanding concerned the need to understand and be understood. This new knowledge was 'interactive' in that it was produced by us all working collaboratively. It was not concerned merely with how neuro-typical people can better support people with Asperger's syndrome, but it was concerned with our mutual lack of understanding and the need to address this.

### **3. New theory and its wider application**

The theory that this research has produced in the triads of understanding and misunderstanding offer a new way of thinking about Asperger's syndrome. However, in producing this theory, we have produced a model which potentially has a much wider applicability. I have identified with other people, further applications of the triads when we have been discussing them. These include using the triads for people with mental health needs, for people with dementia, for children with ADHD, for management situations between the manager and the 'managed' and for anyone in any kind of relationship. I am working on an article with one of the co-researchers exploring how the triads can be used in social work assessments and am also working on a conference for academic staff using the triads in relation to the student experience in Higher Education. This conference will be the main teaching and learning conference of the year and will use the Triad of Understanding to set its themes. The intention of the conference is that each Faculty will develop a plan to respond to the learning from the conference to support a better student experience in the many transitions within Higher Education. The triad has also been used by De Montfort

University to form a framework for the development of learning and teaching expertise. This will form the basis of an application to the Academy of Higher Education for the institution's accreditation of academic development provision<sup>10</sup>.

As can be seen, this model of understanding has a much wider application than the relationship between neuro-typical people and those with Asperger's syndrome. This was a real surprise to myself and the co-researchers. My contemplation of this reminded me of the literature concerning the 'Other' (Foucault, 1977a) and the gaze (Foucault, 1989). I wrote in the Literature Review that 'it is through the identification of the Other that the Same can define itself' (p.55). The Triad of Understanding brings the Same and the Other into one model. It calls for an understanding from all parties involved. It is about seeking an understanding which includes the Other having greater self understanding. It is also concerned with the Other's understanding of the Same. This model does not minimise the differences between the Other and the Same, but its application should help to gain mutual understanding. The 'Other' simply becomes 'Different', rather than 'Other'. Foucault wrote of the 'gaze' and how knowledge is formed through it (Foucault, 1989b). In the gaze, as illustrated by the panopticon (Foucault, 1977) professionals can observe and produce knowledge which in turn can be used to control.

Building on the insights that Foucault's work offers, the triads indicate the importance of the Same and the Other entering into a dialogue to promote mutual understanding. The triads offer a framework for redressing the power imbalance. Instead of professionals observing and then theorising, this model calls for a dialogue. Knowledge is not something to be used and power wielded through it, but it is something to be shared to gain self and mutual understanding. For this reason I think it has universal appeal and application. It is a different way of viewing all relationships in terms of understanding.

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<sup>10</sup> This application is being made in July 2014.

The concepts of the gaze, power and autistic spaces are key concepts in this thesis and they are bound to each other. In Foucault's writing, the gaze is 'the act of seeing' (Foucault, 1989b, p. ix). I cited Foucault in Chapter Two:

Doctor and patient are caught up in an ever-greater proximity, bound together, the doctor by an ever more attentive, more insistent, more penetrating gaze, the patient by all the silent, irreplaceable qualities that, in him (sic), betray-that is, reveal and conceal-the clearly ordered forms of the disease (Foucault, 1989b, pp. 16-17).

In an autistic space, the relationship between a person with Asperger's syndrome and a neuro-typical person must be the reverse of this. The two parties should be 'bound' to each other in a commitment to understand each other. In the physical space of the hospital, the doctors were able to order forms of diseases through subjecting patients to a form of surveillance. The gaze allows for discourse to be formulated. In Chapter Two, I also cited Foucault's 'The History of Sexuality: 1', where he stated that 'Discourse transmits and produces power: it reinforces it, but also undermines it and exposes it, renders it fragile and makes it possible to thwart it' (Foucault, 1998, p. 101). I commented: 'For Foucault, 'It is in discourse that power and knowledge are joined together' (Foucault, 1998, p. 100). It is through the discourse that is produced following the gaze that power and knowledge are able to operate. The Triad of Understanding offers the possibility of a different kind of discourse. It offers the possibility of a mutual 'seeing', a relationship based on mutual understanding rather than one party being subjugated to the other. An autistic space can be created when neuro-typical people and people with Asperger's syndrome understand each other and act upon that understanding. The discourse employed in such a space must be one of understanding and valuing difference rather than encompassing notions of superiority and inferiority. If power is understood as operating through discourse, then employing a framework which is based on mutual understanding rather than the superior position of one party categorizing the other, then the power relationship can be radically altered. In Chapter Four I cited Smith who has suggested an analytical framework for considering power:

- Understanding power relationships
- Exploring power relationships
- Reframing power relationships
- Changing power relationships (Smith, 2008, p. 150).

To create autistic spaces, all four of these must be addressed. Following Foucault, I have considered a specific operation of power in this thesis, which is as it operates through discourse. It is when the relationship between neurotypical people and people with Asperger's syndrome is reframed by the gaze being transformed to being a mutual understanding that the power relationship will be changed. The concept of the gaze is a way of understanding how power works. The Triad of Understanding is a way of exploring the power relationships. To create an autistic space, the power relationships must be reframed and changed. The mutual responsibility of both parties to understand framed in the Triad of Understanding transforms the power relationships and allows for autistic spaces to be created.

#### **4. Implications for service provision**

The research question: 'What support do adults with Asperger's syndrome want?' has been addressed through the development of the Triad of Understanding. Not only has it been addressed but the research presents a challenge to traditional notions of support. If the findings are considered in terms of 'support', people with Asperger's syndrome want support in the three areas of 'me understanding myself', 'me understanding others' and 'others understanding me'. In order for this to be achieved, the findings suggest that a challenge is made to neuro-typical people to take some of the responsibility for improvements in the quality of communication between themselves and people with Asperger's syndrome. Adults with Asperger's syndrome want support to focus on helping them in situations where they do not understand and are not understood. The data has revealed that many services either do not offer this support or do so unsuccessfully. The research suggests that support should be offered in the context of the many two way relationships experienced by the person with Asperger's syndrome rather than just offered to the person with Asperger's syndrome.

As discussed already, sessions are offered about 'autism awareness' to people who support adults with Asperger's syndrome. This research is based on the fact that there are differences between neuro-typical people and people with Asperger's syndrome so this is not denied. The difference in approach is that in this research it was recognised that neuro-typical people are also 'alien' to people with Asperger's syndrome. Implicit in either party recognising or understanding the differences of the other is a need for self understanding. Sessions that look at 'autism awareness' should also consider 'neuro-typical awareness'. Until neuro-typical people consider what it is to be neuro-typical in a world where they are overwhelmingly dominant, it would be difficult to understand what it is to be a person with Asperger's syndrome. Earlier I made a comparison to an understanding of race. In my experience, white students find it difficult to think about their own identity because they are from the dominant culture. In contrast, black students are often much better at reflecting on their identity as black people. In the same way, consideration should be given to self understanding on the behalf of neuro-typical people.

This research is a challenge to service providers to reflect on how they support and work with service users who have Asperger's syndrome. According to this research, people with Asperger's syndrome want to be supported to understand themselves and others better and to be better understood. The triads form the basis for doing this.

### **5. Suggestions for future research**

This research has uncovered areas which would benefit from further research. This includes the learning from the co-production of an autistic research space. Further research involving adults with Asperger's syndrome could use this learning and apply the principles to future research spaces. Future research could consider the triads of understanding and misunderstanding as models which offer a framework to consider support and develop them further. Further research piloting these with people with Asperger's syndrome would further test their suitability.

The 'limitations' section of this chapter outlined that this research did not address issues of age, race, gender or sexual orientation. Further research could explore the influence of these factors in relation to the development of mutual understanding between neuro-typical people and those with Asperger's syndrome.

The application of the triads to other groups of people could be explored, including people with mental health needs, ADHD, dementia as well as people with a learning disability, to cite a few. The application of the triads to inform assessments is also an area where further research could be fruitful.

The triads have been well received by people as evidenced at our conference by service users and people who support them and at occasions when I have talked about the triads. Research which further explores and tests their applications in various contexts would be very useful.

## **6. An ending or a beginning?**

I want to end with providing an update about the co-researchers. In my view, the continuation of the Asperger's Consultation Group, their continued enthusiasm for and commitment to telling other people about the triads of understanding and misunderstanding and their desire in wanting to continue to work together and with me as their 'navigator' is validation of the power of co-produced research. Since we held our conference in 2012, the co-researchers have taught on the Sociology B.A. course at De Montfort University. We have also been accepted as keynote speakers at a conference at the University in September 2014. The conference is using the Triad of Understanding to form the main themes of the conference to consider the experience of all students in Higher Education. The co-researchers have also contributed to a book concerning partnership working (Gosling and Martin, 2012). In addition, we have written a journal article explaining how we worked together and this has been published in *Groupwork* (Martin et al, 2014). We continue to meet regularly and I continue to chair the meetings at their request. We are currently working on the

conference to be held at De Montfort University. We are also working on more co-writing projects. We have had an abstract accepted to write about the Triad of Understanding and its application to social work assessments for The Social Work and Sciences Review, an international journal of applied research. We have also submitted a book proposal to write about the work of the group, the Triad of Understanding and its application to people with Asperger's syndrome.

Herbert, (n.d.) is reported to have said 'There is no real ending. It's just the place where you stop the story'. This research has shown the possibility of adults with Asperger's syndrome being involved in research, not only as participants, but as co-researchers. It has shown what can be achieved when 'non-disabled' researchers work in partnership with service users. It has proposed a new way of understanding Asperger's syndrome, based on mutual understanding. If future research builds on this knowledge, then the 'story' will continue.

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<sup>11</sup> I previously published under the surname ‘Martin’ but have now changed my name to ‘Robinson’

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## Appendix 1

### **Statement of the competence of Jackie Martin to conduct proposed research**

I am a qualified and registered social worker with over fifteen years of experience of working with learning disabled adults and adults on the autistic spectrum. I have undertaken a one year course in understanding autism and have also read widely about the needs of adults with Asperger's syndrome.

I am a skilled communicator and have extensive experience of working with groups and with individuals.

I have published the following:

Martin, J. (2007) *Safeguarding Adults*, Russell House Publishing

Martin, J. and Thompson, S. (2009) *Working with Adults: Values into Practice. A learning and Development Manual*, Russell House Publishing

Martin, J. (2009) 'Inclusive Further Education for people with a learning disability. The perspectives of people with a learning disability' in Bollard, M. (ed) *Intellectual Disability and Social Inclusion*, Elsevier.

My publications are largely concerned with the rights of individuals who are marginalised by society and this theme is the motivation for the proposed research.

I have also presented a conference paper entitled 'Space for Values' and run a model and strategy group in partnership with a service user at the 2009 international conference 'Authenticity to Action-Involving Service Users and Carers in Higher Education'. This work will build on the experience I have gained with working with service users and carers in a participatory way in the development of a post qualifying social work programme at De Montfort University.

**I will be supervised by two researchers, who will ensure that my research is conducted in a professional and ethical manner, goals to which I am committed.**

## Appendix 2

### Information and Consent form for the Planning Group

#### **Purpose of research project**

The research project aims to consult adults with Asperger's syndrome about their views of the services they receive. The project will be managed by a researcher working with a planning group. This group will be key to the project as it will work with the researcher to decide how to obtain the views of other adults with Asperger's syndrome and then how to act on the information once it has been collected.

The researcher is Jackie Martin, who is a lecturer in social work at De Montfort University in Leicester ([jmartin02@dmu.ac.uk](mailto:jmartin02@dmu.ac.uk) 0116 2577743). Jackie used to be a social worker, but is no longer practicing as one. Jackie has a number of family members who have Asperger's syndrome and this has given her real commitment to working towards making services better for people. The research project will be part of Jackie's PhD.

There will not be any payment for taking part in the group, neither is Jackie paid to conduct the research, although as already stated, the project will form part of Jackie's PhD thesis. The primary motivation for this research is to work together to improve the lives of adults with Asperger's syndrome. The responsibilities of the group and the researcher will be outlined below.

If a member of the planning group needs their carer to be present in order to attend, the carer will be welcome to attend the group.

#### **The planning group will have the following responsibilities:**

- Meet with Jackie to discuss the research on a regular basis (to be agreed by the group).
- Together with Jackie, decide how to consult other adults with Asperger's syndrome about their views on the services that they receive.

- Together with Jackie, design questionnaires or other research tools to find out what people think about the services that they receive.
- Together with Jackie, decide how the planning group want to address any issues that they discover through this research, whether this be by means of representation to services or any other course of action that is agreed.
- To respect all other members of the planning group in the way that they speak to each other.
- Listen to the views of each other.
- Agree guidelines for working together.
- Commit to working together to improve the lives of adults with Asperger's syndrome.

**Individual members of the planning group may:**

- Withdraw from the research at any time they want to.
- Complain to Jackie's supervisors if they are unhappy with her behaviour (Roger Smith-email [rsmith01@dmu.ac.uk](mailto:rsmith01@dmu.ac.uk) tel. 0116 2551551 ex. 7109 or Jennie Fleming-email [jfleming@dmu.ac.uk](mailto:jfleming@dmu.ac.uk) tel. 0116 2551551 ex. 7871)

**The researcher has the following responsibilities:**

- To meet regularly with the planning group.
- To work with the planning group to decide how to consult other adults with Asperger's syndrome about their views on the services that they receive.
- To work with the planning group to design questionnaires or other research tools to find out what people think about the services that they receive.
- To respect all other members of the planning group in the way that she speaks to and acts towards them.
- Listen to the views of the group.
- To work with the planning group to agree guidelines to work together to improve the lives of other adults with Asperger's syndrome.
- To keep the identity of individuals in the planning group confidential unless they wish to be identified in any subsequent publications in the way of their choice.



- To write about the project is a way that is respectful and promotes a positive image of adults with Asperger's syndrome.
- To ensure that the planning group act in a way that promotes the overall purpose of the project as expressed above.
- Act in accordance with the Council's policies if any safeguarding issues are highlighted during the project.

### **Confidentiality**

Your identity will be kept confidential in any writings or discussions about the research unless you want to be identified. Any safeguarding issues will be dealt with within the Council's policy and identity cannot be guaranteed if the withholding of it means that someone is put at risk. Any recordings or notes of meetings will be kept in a locked storage cabinet to ensure that no unauthorised person has access to any information.

### **What will happen as a result of the research?**

The research will be written about by Jackie to form part of her PhD thesis. The results may also be written about as part of articles or books. If the research is written about in a journal or book, it will be to share what we have learnt from this research and what happened about the issues you raised about services.

### **Benefits of taking part**

As a member of the planning group, you will have the opportunity to take part in a piece of research which aims to give you and other adults with Asperger's syndrome a 'voice'. You will also be part of deciding how to consult with other adults with Asperger's syndrome and of what to do about any issues that are raised in relation to services.

### **Disadvantages of taking part**

- You will need to be willing to give up some of your time to this project, although it is hoped that you will find this rewarding.
- There is no guarantee about what the project will achieve, only a guarantee that we will work together to try and improve services.

**I have read the information contained in this information and consent form and would like to be a member of the planning group. I understand that this is voluntary and I may withdraw from the group at any time.**

**Signed.....**

**Name.....**

**Date.....**



Appendix 3  
Aspergers Consultation Group Questionnaire

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*Please circle the correct answers unless otherwise stated*

Part A. About you

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1. Are you male or female? Male/female
2. Which age group are you in? 18-29, 30-39, 40-49, 50-59, 60-65, 65 +
3. What is your ethnic origin?
4. Who do you live with?
  - I live alone
  - I live with parent(s)
  - I live with a partner
  - I live with friends,
  - I live with relatives that are not my parents
  - I live in shared accommodation
  - Other

5. What type of accommodation do you live in? Please circle only one

- I live in supported living
- live in a residential unit
- I live in an adult placement scheme
- I live in a private house / flat (either owned or rented)
- I live in a council property or housing association property
- Other

## B. Your Diagnosis

---

*Please note that the questions below should relate to a formal diagnosis from a professional, not a self diagnosis.*

1. Have you got a formal diagnosis of Asperger Syndrome? Yes/no

N.B Please note that if you have not got a formal diagnosis, please do not complete this questionnaire as it is for those who have a formal diagnosis.

2. How old were you when you were diagnosed?

0-5, 6-12, 13-17, 18-29, 30-39, 40-49, 50-65, 65 +?

3. What affect did diagnosis have on your access to services?

- Services decreased for me after I was diagnosed
- Services stayed the same for me after I was diagnosed
- Services increased for me after I was diagnosed
- I didn't have any services before I was diagnosed
- I have never received services
- I was diagnosed when I was young, so can't comment on this

4. When you were diagnosed did you receive any support in connection with your diagnosis? Yes/no

5. If you answered 'yes'-please state what kind of support was it and who gave it to you.

If you answered 'no', please go to question 9.

6. How helpful to you was this support?

Very unhelpful, unhelpful, helpful, very helpful

7. Please state what it was about the support that made it unhelpful, if it did.

8. Please state what it was about your support that made it helpful, if it did.

9. Would you have liked to have had support?

yes/ no/ it was offered and I declined

10. If you had no support but would have liked it, what kind of support would you have liked?

### C. Interacting with people

---

1. Do services help you relate to people?

Not at all, they help a little, they help a lot, I don't receive services

2. Are you receiving any services that are helping you relate to people?

Yes/ no

3. If you stated 'yes', please state which services have helped you relate to people?

4. Please describe what have they done that has helped you relate to people?

5. Please describe what improvements could be made to services to help you relate to people?



#### D. Dealing with the outside world

---

1. Do services help you deal with the outside world, for example places where you might work, study, socialise or shop?

Not at all/ they help a little/ they help a lot/ I don't receive services

2. Please describe how do services help you deal with the outside world, if they do:

3. Please describe what improvement could be made to services to help you deal with the outside world:

#### E. Access to work

---

1. Have you had support in finding work? Yes/no
2. If you answered yes, who provided this support?  
If you answered no, please go to question 6.
3. Please describe what was unhelpful about the support, if anything:
4. Please describe what was helpful about the support, if anything:
5. If there was anything missing from your support which you would have been helpful to you, what was it?
6. If you didn't receive support to find work, what support would you have liked to help you find work?

1. What types of work have you done? Please circle all which are relevant

Self employed/ voluntary supported/ voluntary unsupported/ paid supported/ paid unsupported/ I have never worked

If you have never worked, please go to section G, if you have please answer questions 2, 3 and 4 and then go to section G.

2. If you had support in work-was it helpful?

Yes/ no /I have worked but have never had support in work

3. If it was not helpful, please describe what was unhelpful about it, If you have worked but have not received support, please state 'I have not received support'.
4. If it was helpful, please describe what was helpful about it. If you have worked but have not received support please state 'I have worked but have not received support'.

## G Other information

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*Please use this space to tell us anything about services which you think is important that the questionnaire hasn't addressed.*

## F. Contact information

---

Would you be willing to be interviewed by a member of the Aspergers Consultation Group to find out more about your views of services?

Yes/ no

If yes, please state your name and how you would like to be contacted.

Name:

By which method would you like to be contacted by: e mail/ phone call/ letter

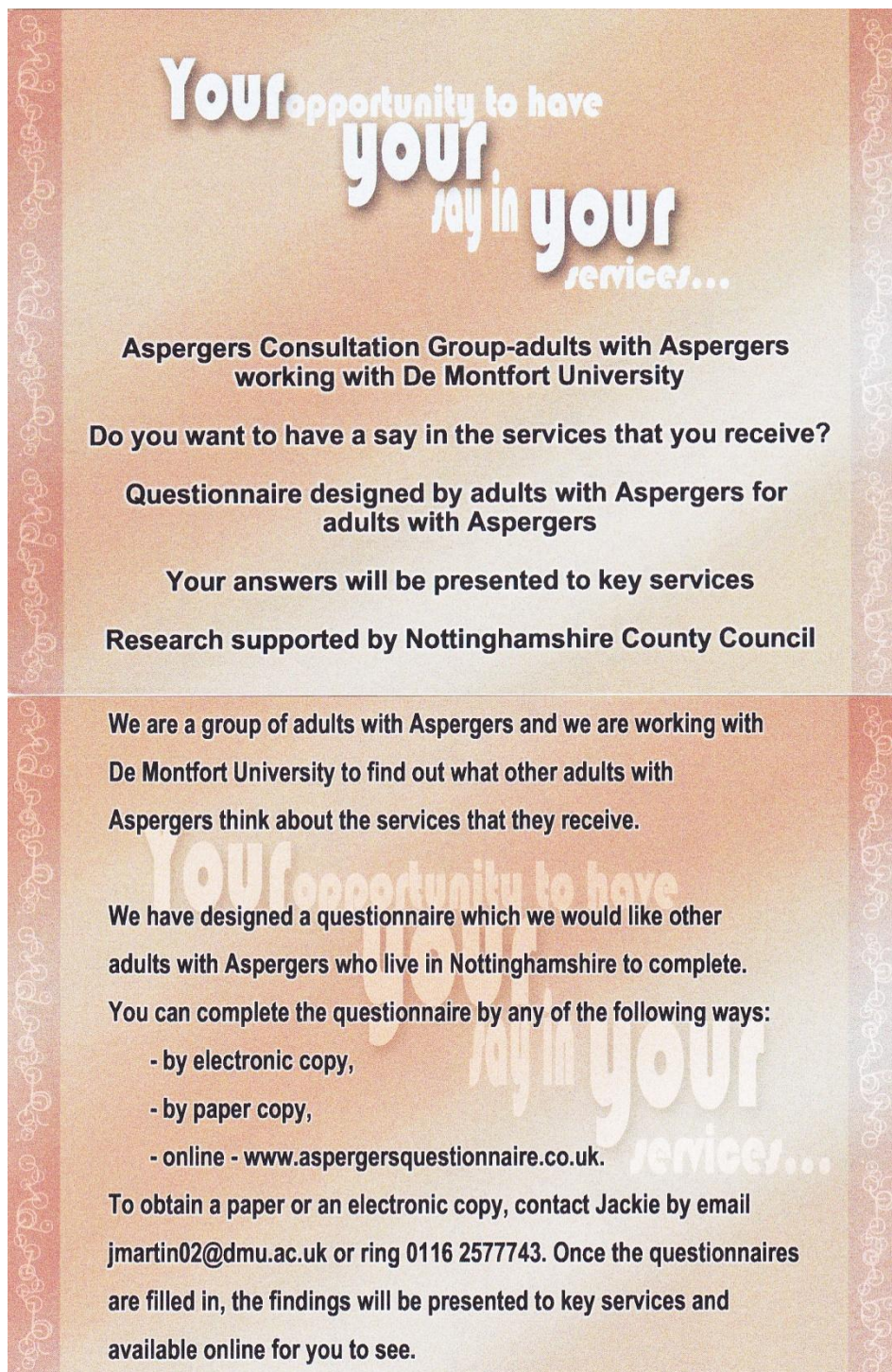
My contact details are:

Thank you for completing this questionnaire.

*The Aspergers Consultation Group.*

## Appendix 4

### Flyer about the questionnaire

The flyer has a light beige background with a decorative border of small, repeating floral or scroll-like patterns in a darker beige color. At the top, the text 'Your opportunity to have your say in your services...' is written in a large, bold, sans-serif font. The word 'Your' is the largest, followed by 'opportunity to have' in a smaller font, then 'your' in a large font, 'say in' in a smaller font, and 'your services...' in a large font. Below this, the text 'Aspergers Consultation Group-adults with Aspergers working with De Montfort University' is written in a bold, sans-serif font. This is followed by the question 'Do you want to have a say in the services that you receive?' in a bold, sans-serif font. Then, 'Questionnaire designed by adults with Aspergers for adults with Aspergers' is written in a bold, sans-serif font. Below that, 'Your answers will be presented to key services' is written in a bold, sans-serif font. Finally, 'Research supported by Nottinghamshire County Council' is written in a bold, sans-serif font. A horizontal line separates this top section from the bottom section. The bottom section starts with 'We are a group of adults with Aspergers and we are working with De Montfort University to find out what other adults with Aspergers think about the services that they receive.' in a bold, sans-serif font. This is followed by 'We have designed a questionnaire which we would like other adults with Aspergers who live in Nottinghamshire to complete.' in a bold, sans-serif font. Then, 'You can complete the questionnaire by any of the following ways:' is written in a bold, sans-serif font. Below this, there is a list of three ways to complete the questionnaire: '- by electronic copy,', '- by paper copy,', and '- online - www.aspergersquestionnaire.co.uk.' in a bold, sans-serif font. The bottom section ends with 'To obtain a paper or an electronic copy, contact Jackie by email jmartin02@dmu.ac.uk or ring 0116 2577743. Once the questionnaires are filled in, the findings will be presented to key services and available online for you to see.' in a bold, sans-serif font.

**Appendix 5**  
**Codes for questionnaire responses**

**Section B**

**Question 5**

- 1: support with benefits
- 2: Occupational Therapy
- 3: Help from Social Services
- 4: Help with Education
- 5. Norsaca
- 6. Early Intervention team
- 7. Social worker
- 8. Psychologist

**Question 7**

- 1: Nothing achieved
- 2: No help or advice

**Question 8**

- 1: formal diagnosis helped with access to services
- 2. Explanation and understanding
- 3. Practical skills
- 4. Communication skills
- 5. I never received help in the early stages

**Question 10**

- 1: Help with identifying and expressing needs
- 2: No flexibility in services
- 3: Bespoke support
- 4. Anything because nothing was available
- 5. Support is required but can't identify what it is
- 6. Talking therapy
- 7. Diagnosis specific support

8. Understanding of Aspergers
9. Managing/coping with Aspergers
10. Being understood
11. Support with independent living skills
12. Support with social situations
13. Managing behaviour in public

### **Section C**

#### **Question 3** (Use name of service)

- 1: Ingeus
- 2: NCC Aspergers Team
- 3: Support Worker
- 4: Youth Club
5. Befriending
6. Day services
7. Women's Group
8. Charity shop volunteer
9. Quality conversations
10. Counselling from social worker

#### **Question 4** (how they help you)

- 1: help with phone calls
- 2: Befriending
- 3: Increase social circles
- 4: help with coping with difficult situations
- 5: help with understanding neuro typical behaviour
- 6: showing understanding

#### **Question 5**

- 1: form filling which leads nowhere

- 2: Services should have training in Aspergers and offer the training
- 3: Support from services in understanding neuro typical behaviour
4. Not interested in relating to people
5. Anything as there is nothing available
6. Communication skills for those with Aspergers
7. Communication skills for NTs for family and friends
8. Someone to talk to
9. More integration with other people with Aspergers

## **Section D**

### **Question 2**

- 1: making phone calls on your behalf
- 2: helping you structure your own phone calls
- 3: help with form filling
- 4: being emotionally supported
- 5: confidence building
6. Help with finances
7. Gaining experience in dealing with the outside world
8. Understanding what has happened in the outside world
9. communication and behaviour with neuro typical people
10. Predicting what happens in the outside world

### **Question 3**

- 1: Lack of promotion and awareness of services
- 2: no improvements necessary
3. No services needed
4. Instant access service for emergencies (pre emptive)
5. Coaching to deal with the outside world
6. Independent living skills
7. Money management
8. Learning social skills and behaviour in public



9. Help understanding the unwritten rules of relationships
10. confidence building and self esteem
11. learning practical skills hands on

## **Section e**

### **Question 2**

1. Jobcentre Plus
2. Ingeus
3. Mencap
4. Connexions
5. Family and friends
6. Readyforwork team
7. Norsaca
8. Social Services

### **Question 4**

- 1: Practical job application skills
2. Help finding a job
- 3.. Help finding voluntary work
4. Emotional support
5. Goal setting

### **Question 6**

- 1: no help given
- 2: do it yourself
- 3: support to find work or not applicable
- 4: guaranteed employer equality
5. Fear of not being listened to
6. Advocacy for difficulties
7. Advocacy for skills
8. Help looking for a job and training

## **Section F**

### **Question 3**

1. The answers didn't make much sense
2. The structure of the support isn't helpful
3. Not having tasks explained

### **Question 4**

Work therapy

1. Graduated help
2. Reassurance –having someone to fall back on
3. Person 19 (question possibly misread)

### **Section G**

1. Early diagnosis is important
2. Professionals recognising Aspergers
3. Recognising it as a disability
4. People with Aspergers are equal people
5. Don't make assumptions about my diagnosis
6. All services should be open
7. No connection between services
8. Awareness of services
9. More positive stories
10. Relationship guidance
11. Guidance for getting on with life e.g. having a pet
12. Support for families to accept Aspergers, taking into consideration the culture
13. Recognising it as an ability
14. Lack of awareness of Aspergers in society
15. Services are focused on children
16. Freedom to make own decisions
17. Self help service with access to professionals
18. Meetings should be Asperger led but not carer led
19. Separate support for people with Aspergers and carers

**Appendix 6**  
**Focus group questions and prompts**

**Questions and prompts for focus groups for Aspergers Consultation Group research**

**1. Me understanding myself**

**a) How important is it to you that you understand yourself?**

- Do you feel that you do understand yourself?
- What has prevented you from understanding yourself?
- What has helped you understand yourself?

**b) Did diagnosis aid you in understanding yourself?**

- What was the process of diagnosis like for you?
- How did you feel when you were being diagnosed?
- Was there anything about your diagnosis that you found confusing?

**c) Has diagnosis changed the way you understand yourself at all?**

- In what ways did diagnosis help you to understand yourself?
- Did anyone support you with understanding your diagnosis? If so, did this help or hinder?
- What was it about your diagnosis that helped you understand yourself?

**d) How do you feel about having Aspergers?**

- Do you feel it is a positive or negative thing?
- Do you think that Aspergers is a disability or not?
- If it isn't a disability, what is it?
- Are you proud of having Aspergers or is it something you don't like to talk about?

**e) Why is it you feel like that?**

- Has anyone influenced how you feel about having Aspergers?

- Have you previously discussed having Aspergers with other people with Aspergers? If so, how has this influenced how you feel about yourself?

## **2. Others understanding me**

### **a) How important is it to you that other people understand you?**

- Do you think that other people do understand you?
- How can you tell if people understand you?
- Do you expect other people to understand you?
- What goes happens for you when you are misunderstood?
- How does it help you when people understand you?

### **b) What do you want other people to understand about you?**

- Do you want to be seen as having difficulties or to be seen as good at some things or a mixture of the two?
- Do you want different people to understand different things about you e.g. family member s to understand different things from friends or people at work/college?
- Do you want to be seen as disabled?

### **c) In your experience what has helped other people understand you?**

- Have you been able to support people in understanding you better?
- Have family members been able to help with other understanding you?
- Have people read books etc about Aspergers that you know and if so, do you think this has helped or not?

## **3. Me understanding others (people without Aspergers or autism)**

### **a) How important is it to you that you understand others?**

- Do you think that you do understand other people?
- What has helped you understand other people better?
- Why do you think it is important that you understand other people?
- What goes happens when you don't understand other people?

**b) To what extent do you understand other people?**

- Think about different people-family, friends, people you work or study with, neighbours-how much do you understand these people? (ask about one at a time)
- Do you understand why people say some of the things that they do to you?
- Do you understand how other people think?
- Do you understand how other people behave?

**C) How have you been able to understand other people?**

- What support have you had in understanding other people? Has this helped you?
- Have you read anything about the differences between people with Aspergers and other people? If so, has this helped you understand other people more?
- Have you talked to other people with Aspergers about other people and if so, has this helped you understand them?

## **Appendix 7**

### **Letter inviting participants to take part in focus groups and individual interviews**

De Montfort University,  
Hawthorn Building,  
The Gateway,  
Leicester,  
Le1 9BH

Dear

Thank you for completing the Asperger's Consultation Group questionnaire, your response has been very helpful. We would also like to thank you for agreeing to take part in a follow up interview. Based on our findings we have decided that a focus group may produce better results than interviews. We would like to get together a small group of people with Aspergers to discuss the themes found in the questionnaire responses. How much you contribute is entirely up to you, you can speak as and when you feel comfortable to do so. We hope you feel able to take part in this but if you do not feel able to do this, please don't worry as you can still voice your opinion as we can arrange an individual interview.

There are two sessions to choose from, you can choose to attend the one that is most convenient for you. We understand that you may want to bring someone along to support you, please feel free to do so. Each session is two and a half hours long but we will stop half way for a break and maybe a biscuit! The sessions are being facilitated by two members of the group who have Asperger's syndrome plus Jackie who is helping to conduct the research. We would appreciate if you could let us know either by filling in the form below

or replying by email which session you would like to attend and if you are bringing someone to support you. Thank you for your time, we look forward to meeting you.

**Session One- Friday 7<sup>th</sup> October 2011, 2pm-4.30pm. This session will be at :  
Details removed to safeguard confidentiality**

**Session Two- Thursday 20<sup>th</sup> October 2011 6pm-8.30pm. This session will be at:  
Details removed to safeguard confidentiality**

**Please note that if you would like to contact me, my address is at the top of this letter and my email address and telephone numbers are at the end of the letter.**

## **Appendix 8**

### **Information sheet for focus groups and individual interviews**

Dear Participant,

We would like to invite you to take part in the focus groups for adults with Asperger's syndrome. Before you decide to take part you need to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully.

#### **What is the study about?**

A group of adults with Asperger's syndrome have been working with Jackie Martin to develop research into what other adults with Asperger's syndrome think about the services that they receive. The first part of this research was to develop a questionnaire and the responses to these were then analysed by the group. Based on the answers to the questionnaire the group have developed a set of questions that they would like to discuss with other adults with Asperger's syndrome in focus groups and it is to one of these that you are invited.

#### **What will taking part in the study mean?**

A set of questions to be discussed at the focus groups are attached to this information sheet. The focus group session will take part in two halves of approximately an hour each with a half hour break in the middle for a drink. Jackie will ask questions and the members of the focus group will then discuss what they think about the issues raised. Jackie will record the sessions so that they can be transcribed later so that what you and the other members of the focus groups say is not lost. When the discussions have been typed up, the Asperger's Consultation Group will meet to look at what you have said and analyse this to help us understand more about how people want to be supported.

#### **Why have I been invited?**



You have been invited because you are an adult with Asperger's syndrome and we want to find out what you think about the questions to be discussed.

**Do I have to take part?**

You do not have to take part if you don't want to. We hope you will feel able to discuss what you think in the group, but if you don't want to answer, that is fine.

**What are the possible disadvantages and risks of taking part?**

We are unable to pay you for your time in the focus group. We do hope though that you think it will be an enjoyable experience and that you will benefit from discussing how you think about having Asperger's syndrome with other adults with Asperger's syndrome.

**What are the possible benefits of taking part?**

You will be helping us by giving us more information for our research. We are planning to hold an event to tell services about what we have found out and so this could have real benefits for adults with Asperger's syndrome.

**Will my taking part in the study be kept confidential?**

Yes, taking part is confidential. You will not be named in the write up of the research and people in the focus group will be asked not to tell other people any confidential information about you.

**What will happen to the results of the research study?**

We intend to hold a conference to tell services what we have found out about what people with Asperger's syndrome want from services. We hope the results will be published in journals and in a book.

**Complaints about the study**

If you have a concern about any aspect of this study, you should ask to speak to the research team who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do so through De Montfort University's complaints procedure. Contact details can be obtained from the research office in the Faculty of Health and Life Science.

**Who is organising and funding the research?**

The research has been organised by Jackie Martin who is a Principal Lecturer in Social Work at De Montfort University together with the Asperger's Consultation Group who are Katrina Fox, Duncan MacGregor and Laura Hickman.

**Who has reviewed the study?**

The Ethics Committee for the Faculty of Health and Life Sciences at De Montfort University.

**Further information and contact details**

**If you want more information then please contact:**

Jackie Martin,

De Montfort University, Hawthorn Building, The Gateway, Leicester, Le1 9BH

Tel: 0116 2577743. Email [jmartin02@dmu.ac.uk](mailto:jmartin02@dmu.ac.uk)

## Appendix 9

### Consent form for focus groups and individual interviews

- I agree to take part in the focus group discussion arranged by Jackie Martin and the Aspergers Consultation Group.
- I have been given a copy of the questions so I know what the discussion will be about.
- I agree to respect other people in the focus group in how I talk to them
- I agree to keep what other people have said in the focus group as confidential
- I agree to the discussion being recorded and the conversations being used by the Aspergers Consultation Group for part of their research into what people with Aspergers want from services
- I agree to Jackie using the information from the focus group for her PhD thesis but not using my name (unless I want her to).
- I will be given a copy of this consent form to keep for my own information

Name of participant.....

Signed.....

Researcher.....

Signed by researcher.....

Date.....

Should you have any reason to complain about your involvement in this research,  
please contact either:

Roger Smith by email [rsmith01@dmu.ac.uk](mailto:rsmith01@dmu.ac.uk) tel 0116 2577109 or

Jennie Fleming email [jflenming@dmu.ac.uk](mailto:jflenming@dmu.ac.uk) or tel 0116 2577873

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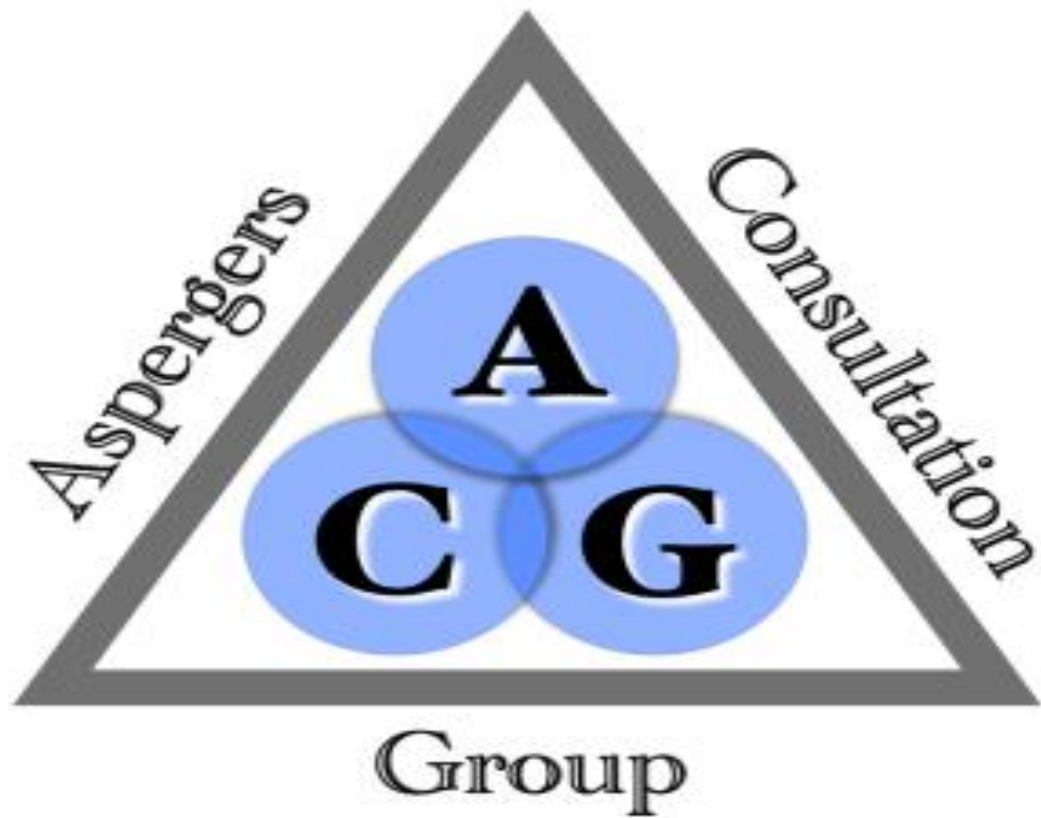
- I no longer want to take part in this study
- I will attend Session One- Friday 7<sup>th</sup> October 2011, 2pm-4.30pm at  
Workshop
- I will attend Session Two- Thursday 20<sup>th</sup> October 2011 6pm-8.30pm at  
Mansfield
- I am unable to attend either session and would like an individual  
interview

**Please tick which option applies to you and send back in the envelope  
provided.**

Name.....

## Appendix 10

Logo for the group that one of the co-researchers designed



## **Appendix 11**

### **Codes from focus groups and individual interviews**

1. Expresses a definite need for personal understanding.
  - 1A Expresses a need for understanding others: language/emotion
  - 1B. Self acceptance
  - 1C Need for others to understand me
2. 'Learning process' indicates that knowing yourself is an ongoing process.
3. Separates understanding Aspergers and understanding yourself.
4. Without prompting refers to others understanding me which indicates the significance of this theme.
5. When I cannot understand myself I feel 'out of control'.
6. Being able to explain behaviour to others and have that accepted helps me feel more in control.
7. Explaining myself to others relies on me understanding myself.
8. Confusion surrounding identity hinders the understanding of myself.
  - 8A Being clear about identity helps me understand myself
9. A conscious effort to improve behaviour to be seen as acceptable and improve relationships.
10. When you most need someone to understand you, you are least able to explain yourself.
11. Misdiagnosis and late diagnosis hindered self understanding.
12. Lack of explanation from others affects your ability to understand yourself.
13. Minimal post diagnosis explanation.
14. Me not understanding myself creates conflict.
15. Others not understanding me creates conflict.
16. Others misunderstanding me can lead to bullying which leads to issues understanding myself.
17. Me not understanding others can also lead to conflict.
18. Individual research into Aspergers is beneficial.

- 18A Individual research restricts what you think you can do.
19. Diagnosis is a relief as it enables further understanding.
20. Coping strategies are important.
21. *Shared* experiences with other people with Aspergers are helpful.
22. Different and conflicting messages make you incapable of defining yourself which in turn affects other people's ability to understand you.
23. The attitudes of people without Aspergers influences my sense of identity.
24. Even if you gain a good understanding of yourself, can you trust other people to have a good understanding of you.
25. Others understanding me relies upon their willingness.
- 25A. Your understanding of yourself relies on the willingness of others.
26. There is an expectation that people won't understand.
27. Having to explain behaviour all the time.
28. It's important to people with Aspergers that they are seen as individuals.
29. I do not want to be seen as disabled. 29A. I do want to be seen as disabled
30. Somebody explaining what has happened/what is happening can be helpful.
- 30A. Somebody explaining what has happened to a non-autistic third person can be helpful
31. I find it hard to understand other people.
32. There are two types of people. Neurotypical and Aspergers.
33. Understanding role in situation
34. Solid example of how triangle could benefit people
35. It doesn't matter if people don't want to understand me, but I am happy to explain myself if they do.
36. Have to be more conscious of behaviour if got Aspergers
37. People with Aspergers are better in some areas.
38. Don't want to be seen as an outsider.
- 38A Want to be seen as different
- 38B Distance yourself as a protective measure
39. A feeling that diagnosis can hold you back



- 40. Aspergers brings out intellectual qualities
- 41. People with Aspergers expected to be clever but not able to do anything with it.
- 42. People with Aspergers make a conscious effort to understand the whole picture of how people feel.
- 43. People with Aspergers avoid situations that they aren't prepared for.
- 44. Aspergers is a part of a person, not the whole
- 45. Other health or mental health conditions influence behaviour
- 46. Self sufficient
- 47. Proud of Aspergers identity



## Appendix 12

### Codes allocated to themes from triads of understanding and misunderstanding

#### Triad of Understanding

##### Me understanding myself

1. Expresses a definite need for personal understanding.
2. 1B. Self acceptance
3. 19. Diagnosis is a relief as it enables further understanding.
4. 21. *Shared* experiences with other people with Aspergers are helpful.
5. 25A. Your understanding of yourself relies on the willingness of others-also in others understanding me
6. 30. Somebody explaining what has happened/what is happening can be helpful-this is in all three themes
7. 35. It doesn't matter if people don't want to understand me, but I am happy to explain myself if they do-also in others understanding me
8. 45. Other health or mental health conditions influence behaviour
9. 18. Individual research into Asperger's is beneficial
10. 2. 'Learning process' indicates that knowing yourself is an ongoing process (note-in discussion, we decided that people with Aspergers have to evolve in relation to changing situations)
11. 7. Explaining myself to others relies on me understanding myself-also in others understanding me
12. 9. Conscious effort to improve behaviour to be seen as acceptable and improve relationships-also in me understanding others
13. 27. Having to explain behaviour all the time-also in others understanding me
14. 33. Understanding role in situation-in all three
15. 20. Coping strategies are important.
16. 36. Have to be more conscious of behaviour if got Aspergers-also in me understanding others
17. 38B. Distance yourself as a protective measure-also in me understanding others

18. 43. People with Aspergers avoid situations that they aren't prepared for.

### **Me understanding others**

1. 1A. Expresses a need for understanding others: language/emotion
2. 30. Somebody explaining what has happened/what is happening can be helpful-this is in all three themes
3. 33. Understanding role in situation-in all three
4. 42. People with Aspergers make a conscious effort to understand the whole picture of how people feel.
5. 9. A conscious effort to improve behaviour to be seen as acceptable and improve relationships-also in me understanding myself
6. 36. Have to be more conscious of behaviour if got Aspergers-also in me understanding myself
7. 34. Solid example of how triangle could benefit people-in all three

### **Others understanding me**

1. 1C. Need for others to understand me
2. 4. Without prompting refers to others understanding me which indicates the significance of this theme.
3. 25. Others understanding me relies upon their willingness.
4. 25A. Your understanding of yourself relies on the willingness of others-also in me understanding myself
5. 30. Somebody explaining what has happened/what is happening can be helpful-this is in all three themes
6. 30A. Somebody explaining what has happened to a non-autistic third person can be helpful
7. 33. Understanding role in situation-in all three
8. 35. It doesn't matter if people don't want to understand me, but I am happy to explain myself if they do-also in me understanding myself
9. 6. Being able to explain behaviour to others and have that accepted helps me feel more in control.

10. 7. Explaining myself to others relies on me understanding myself-also in me understanding myself
11. 27. Having to explain behaviour all the time-also in me understanding myself
12. 34. Solid example of how triangle could benefit people-in all three

### **Triad of Misunderstanding**

#### **Me misunderstanding myself**

1. 12. Lack of explanation from others affects your ability to understand yourself-also in others understanding me
2. 16. Others misunderstanding me can lead to bullying which leads to issues understanding myself-also in others understanding me
3. 13. Minimal post diagnosis explanation
4. 11. Misdiagnosis and late diagnosis hindered self understanding
5. 18A. Individual research restricts what you think you can do
6. 14. Me not understanding myself creates conflict.
7. 5. When I cannot understand myself I feel 'out of control'.

#### **Me misunderstanding others**

1. 31. I find it hard to understand other people
2. 38B. Distance yourself as a protective measure-also in me understanding myself

#### **Others misunderstanding me**

1. 10. When you most need someone to understand you, you are least able to explain yourself.
2. 12. Lack of explanation from others affects your ability to understand yourself-also in me understanding myself

3. 16. Others misunderstanding me can lead to bullying which leads to issues understanding myself-also in me understanding myself
4. 17. Me not understanding others can also lead to conflict.
5. 24. Even if you gain a good understanding of yourself, can you trust other people to have a good understanding of you.
6. 26. There is an expectation that people won't understand.
7. 15. Others not understanding me creates conflict.
8. 22. Different and conflicting messages make you incapable of defining yourself which in turn affects other people's ability to understand you-also in me understanding myself

## **Appendix 13**

### **Coding of data from focus groups and individual interviews categorised into themes from triads of 'Understanding', 'Understanding leads to coping' and 'coping'**

#### **Triad of Understanding**

##### **Me understanding myself**

'Information about Aspergers, other people with Aspergers' experience and explanations from those around me help me in understanding myself. A complete picture of myself helps me to develop coping strategies that in turn help me deal with life.'

##### **Understanding**

- 19. 1. Expresses a definite need for personal understanding.
- 20. 1B. Self acceptance
- 21. 19. Diagnosis is a relief as it enables further understanding.
- 22. 21. *Shared* experiences with other people with Aspergers are helpful.
- 23. 25A. Your understanding of yourself relies on the willingness of others-also in others understanding me
- 24. 30. Somebody explaining what has happened/what is happening can be helpful-this is in all three themes
- 25. 35. It doesn't matter if people don't want to understand me, but I am happy to explain myself if they do-also in others understanding me
- 26. 45. Other health or mental health conditions influence behaviour
- 27. 18. Individual research into Asperger's is beneficial

##### **Understanding leading to coping**

- 1. 2. 'Learning process' indicates that knowing yourself is an ongoing process (note-in discussion, we decided that people with Aspergers have to evolve in relation to changing situations)
- 2. 7. Explaining myself to others relies on me understanding myself-also in others understanding me

3. 9. Conscious effort to improve behaviour to be seen as acceptable and improve relationships-also in me understanding others
4. 27. Having to explain behaviour all the time-also in others understanding me
5. 33. Understanding role in situation-in all three

#### **Coping**

1. 20. Coping strategies are important.
2. 36. Have to be more conscious of behaviour if got Aspergers-also in me understanding others
3. 38B. Distance yourself as a protective measure-also in me understanding others
4. 43. People with Aspergers avoid situations that they aren't prepared for.
5. 46. Self sufficient
6. 34. Solid example of how triangle could benefit people-in all three

#### **Me understanding others**

'It is important to understand other people's language and behaviours. It helps me to understand what my role is and I cope by adapting my behaviour to improve my relationships.'

#### **Understanding**

8. 1A. Expresses a need for understanding others: language/emotion
9. 30. Somebody explaining what has happened/what is happening can be helpful-this is in all three themes
10. 33. Understanding role in situation-in all three
11. 42. People with Aspergers make a conscious effort to understand the whole picture of how people feel.

#### **Coping**

1. 9. A conscious effort to improve behaviour to be seen as acceptable and improve relationships-also in me understanding myself



2. 36. Have to be more conscious of behaviour if got Aspergers-also in me understanding myself
3. 34. Solid example of how triangle could benefit people-in all three

### **Others understanding me**

'It is important that others understand me. When people understand me, they can explain things to me and then I can cope a bit better. I can help people to understand me by explaining things from my perspective, which overall improves my relationships.'

### **Understanding**

13. 1C. Need for others to understand me
14. 4. Without prompting refers to others understanding me which indicates the significance of this theme.
15. 25. Others understanding me relies upon their willingness.
16. 25A. Your understanding of yourself relies on the willingness of others-also in me understanding myself
17. 30. Somebody explaining what has happened/what is happening can be helpful-this is in all three themes
18. 30A. Somebody explaining what has happened to a non-autistic third person can be helpful
19. 33. Understanding role in situation-in all three
20. 35. It doesn't matter if people don't want to understand me, but I am happy to explain myself if they do-also in me understanding myself

### **Understanding leading to coping**

1. 6. Being able to explain behaviour to others and have that accepted helps me feel more in control.

### **Coping**

1. 7. Explaining myself to others relies on me understanding myself-also in me understanding myself
2. 27. Having to explain behaviour all the time-also in me understanding myself
4. 34. Solid example of how triangle could benefit people-in all three

### **Triad of Misunderstanding**

#### **Me misunderstanding myself**

‘Confusion arises when I misunderstand myself. I find it difficult to explain myself to others and they find it difficult to understand me. This confusion can lead to conflict and personal distress.’

#### **Misunderstanding**

6. 12. Lack of explanation from others affects your ability to understand yourself-also in others understanding me
7. 16. Others misunderstanding me can lead to bullying which leads to issues understanding myself-also in others understanding me
8. 13. Minimal post diagnosis explanation
9. 11. Misdiagnosis and late diagnosis hindered self understanding
10. 18A. Individual research restricts what you think you can do

#### **Misunderstanding leads to not coping**

1. 14. Me not understanding myself creates conflict.
2. 5. When I cannot understand myself I feel ‘out of control’.

#### **Not Coping**

#### **Me misunderstanding others**

‘When you find it hard to understand others, you find it hard to cope.’

#### **Understanding**

3. 31. I find it hard to understand other people.

#### **Coping**

1. 38B. Distance yourself as a protective measure-also in me understanding myself

### **Others misunderstanding me**

#### **Misunderstanding**

9. 10. When you most need someone to understand you, you are least able to explain yourself.
10. 12. Lack of explanation from others affects your ability to understand yourself-also in me understanding myself
11. 16. Others misunderstanding me can lead to bullying which leads to issues understanding myself-also in me understanding myself
12. 17. Me not understanding others can also lead to conflict.
13. 24. Even if you gain a good understanding of yourself, can you trust other people to have a good understanding of you.
14. 26. There is an expectation that people won't understand.

#### **Misunderstanding leads to not coping**

1. 15. Others not understanding me creates conflict.

#### **Not Coping**

1. 22. Different and conflicting messages make you incapable of defining yourself which in turn affects other people's ability to understand you-also in me understanding myself

**Appendix 14**  
**Conference flyer**

**Conference – ‘Reclaiming the triangle’ –  
an alternative and innovative way of looking at Asperger syndrome**

A 2 year research project between The Asperger Consultation Group and De Montfort University supported by Nottinghamshire County Council. The project has been an excellent example of service user participation. The question the project addressed was:

**‘How do adults with Asperger Syndrome want to be supported?’**

The findings will be presented by the researchers from the Asperger Consultation Group and De Montfort University.  
This will be of interest to:

- adults with Asperger Syndrome
- families of children, young people and adults with Asperger syndrome
- social care and health professionals working with children and adults with Asperger syndrome
- carers offering support to adults and children with Asperger syndrome
- managers of services supporting adults and children with Asperger syndrome
- staff in residential settings supporting children and adults with Asperger syndrome
- staff in schools with pupils with Asperger syndrome

**Wednesday June 27th 1.00pm-4.00pm**

**Assembly Room, County Hall, West Bridgford, Nottingham, NG2 7QP**

**The conference is free**

**Booking forms are available by emailing [jmartin02@dmu.ac.uk](mailto:jmartin02@dmu.ac.uk)**

## **Appendix 15**

### **Case studies for Reclaiming the Triangle Conference**

1. Dot is a 28 year old female with Aspergers. She has recently found out that her child hood friend has just had a baby. Although she is pleased for her friend, she is struggling to cope with her feelings of being left behind. Dot had not realized that the dynamics of her friendship would change and this has left her feeling rejected.

How might the Triad of Understanding be helpful in this situation?

2. Catherine is a 20 year old female with Aspergers. She has finished college and doesn't know what to do next. She would like to get a job but doesn't know what she wants to do. She is feeling lost and confused. Routine is very important for Catherine and this is a particularly hard time for her as she feels she has lost her routine. She is starting to think about what she could do next.

How might the Triad of Understanding be helpful in this situation?

3. Alan is a 53 year old male with Aspergers. He works as a sales assistant in a supermarket. He is well educated and well spoken and is very efficient at his job. The company would like to promote Alan to a more senior role. Alan doesn't feel comfortable and would prefer to stay where he is. Alan feels under pressure to take the new position as his work colleagues would jump at the chance. This has increased Alan's anxiety levels around his work and he is finding it increasingly difficult to function in his role.

How might the Triad of Understanding be helpful in this situation?

4. Edward is a 35 year old male with Aspergers. He has a girlfriend, Marjorie, who he has known for a number of years. Marjorie is neuro typical. Marjorie has just moved in to live with Edward in his flat. Edward is struggling with the impact of sharing his space with someone else. Edward has always had difficulty adapting to change. Edward's flat is very organized and everything has its own place. Making room for Marjorie's belongings is causing distress to Edward and Marjorie is confused by his reactions.

How might the Triad of Understanding be helpful in this situation?

5. Monica is a 42 year old woman who was diagnosed as having Aspergers when she was 39 years old. She has worked as an administrator but has experienced high levels of anxiety and at times has been unable to cope which have resulted in times off work with stress/anxiety. She never understood, prior to her diagnosis why this was occurring. She initially felt a sense of relief when she was diagnosed as it answered some questions for her, but is now confused about her identity and who she is.

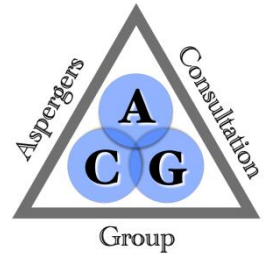
How might the Triad of Understanding be helpful in this situation?

**Appendix 16**  
**Conference feedback form**

Reclaiming the Triangle

27<sup>th</sup> June 2012

Feedback form



Do you have a formal diagnosis of Aspergers Syndrome? (please tick)

Yes ☐ No ☐

What have you most enjoyed about the conference?

What is the most important thing you've learnt from the conference?

How could you implement the Triad of Understanding in your everyday life?

Is there anything we could do differently for future conferences?